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Jordanian parents of young children with disabilities:
Perspectives on care, coping and service provision

Mizyed Abdelfattah Ahmad Hyassat

Submitted to the University of Wales in fulfilment of the requirements for the Degree
of Doctor of Philosophy

Swansea University

May 2012

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Abstract

Researchers in the field of special education have devoted increasing attention to establishing effective programmes for children with disabilities as early as possible which would meet the needs of these children's families and involve mutual partnerships between families and service providers. This has resulted in greater awareness of the necessity of seeking input from parents when planning, delivering, and evaluating such services.

This qualitative study examines the experiences of Jordanian parents of young children with disabilities regarding the provision of services for their children, and explores parents' perspectives on caring for disabled children in Jordan.

A qualitative design was employed to achieve the study's purposes. 53 semi-structured interviews were carried out with 64 parents of young children with disabilities. Thematic analysis techniques were used to examine the data collected from these interviews. Four major overlapping themes emerged from the analysis, namely: parents' experiences of health care services, access to special education services and support, kindergartens for children with disabilities, and parenting disabled children in Jordan.

The study found that the position of Jordanian parents has many similarities to that reported for parents in Western countries. Parents generally had negative experiences with health care practitioners from the time that their children's disabilities were first suspected. Parents struggled with the availability, accessibility, and affordability of educational services and support offered for them and their young disabled children. With regard to kindergartens, although parents were happy that there were designated places for their young disabled children to receive educational services, several negative comments were made relating to kindergarten staff and environments. As a result of caring for disabled children, parents encountered challenges such as unstable family relationships, fears for the future, financial burdens, stress, and stigma. Additionally, parents felt that they received insufficient support. These factors all suggest that parents' needs were not being met.

Declarations

I declare that this work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

This thesis is the result of my own investigations, except where otherwise stated and that other sources are acknowledged by footnotes giving explicit references and that a bibliography is appended.

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary page to be made available to outside organisations.

Signed _____ (candidate)

Date 29/07/2012

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Dedication

I dedicate this thesis to my father who died in the mid of May 2009. May Allah have mercy upon his soul and grant him a place in the highest heaven beside the prophet Mohammad and his companions.

List of commonly used abbreviations

| | |
|--------|--|
| ASD | Autism Spectrum Disorder |
| CBR | Community-Based Rehabilitation |
| CEDD | Centre for Early Detection of Disabilities |
| DfES | Department for Education and Skills |
| EBD | Emotionally and Behaviourally Disturbed |
| ERfKE | Education Reform for the Knowledge Economy |
| GP | General Practitioner |
| GSD | General Statistics Department |
| HCAPD | Higher Council for the Affairs of Persons with Disability |
| HKJ | Hashemite Kingdom of Jordan |
| JD | Jordanian Dinar |
| LED | Local Educational Directors |
| MoE | Ministry of Education |
| MoH | Ministry of Health |
| MoHE | Ministry of Higher Education |
| MoSD | Ministry of Social Development |
| SLCD | Speech, Language, and Communication Difficulties |
| UAE | United Arab Emirates |
| UK | United Kingdom |
| UNESCO | United Nations Educational, Scientific, and Cultural Organization. |
| UNRWA | United Nations Relief and Works Agency |
| USA | United States of America |
| USAID | United States Agency for International Development |
| WHO | World Health Organisation |

Chapter one: Introduction to the thesis

1:1 Introduction

Early intervention is the cornerstone of the field of special educational services, as it promotes the development of young children who have special needs or are considered at risk, and empowers their parents (Carpenter, 2005; Bailey *et al.*, 2004a; Brambring *et al.*, 1996; Feldman, 2004; Wall, 2003). Published research indicates that parents or carers of those children encounter numerous challenges in their daily routines such as stress, stigma, and high physical and financial demand (Brett, 2004; Chell, 2006; Green, 2003; Oelofsen and Richardson, 2006; Rogers, 2007; Voysey, 1975). It is therefore argued that when planning for such programmes, parental accounts should be taken into consideration to create services that sufficiently meet parents' needs (Bailey *et al.*, 1999; Carpenter, 2007; Guralnick, 2005).

The existing literature uses a wide range of terms to refer to early intervention programme such as early intervention, early intervention services, pre-school provision for children with disabilities, early special education services, and early intervention provision. These terms generally encompass the health, social, psychological, and educational services available to children with disabilities or children who are susceptible to developmental delays, and to the parents of those children. Consistent with the literature, these terms will be used interchangeably in this thesis.

Several studies have been carried out regarding the quality of early intervention services (Checker *et al.*, 2009; Crawford and Simonoff, 2003; King *et al.*, 2001; Rodger *et al.*, 2008; Avis and Reardon, 2008; Summers *et al.*, 2005b). The ways in

which these services are delivered, including service providers' interactions with families and their responsiveness to families' needs (Dunst *et al.*, 2007), are key factors influencing parental satisfaction with these services. Parents' perspectives are a commonly used and effective basis from which to investigate the nature of early intervention services.

Disability consists of a diverse collection of conditions. These conditions become apparent at different ages and in different ways; some are obvious at birth while others may not be diagnosed until the child has enrolled in an educational setting or even until after some years of observation. Some conditions will be diagnosed by medical practitioners, while others may fall within the expert jurisdictions of psychologists or teachers. Despite the diversity of disability, the existing framework of institutional provision in Jordan means that children are allocated to broad classes that each comprises a heterogeneous grouping of conditions. Children who present with very different signs and symptoms, and varying degrees of perceived severity, are in practice allocated to categories according to the nature of the care settings available for them. For example, children with Down's syndrome, Fragile X syndrome, autism and cerebral palsy – are commonly treated in the same facilities, and considered for pragmatic purposes to fall under the general category of 'intellectual disability' (for more detail of the sample see Table 5 on pp 85-86). The sample utilised for this research was identified through the three main types of organisational settings existing in Jordan, which respectively made provision for children who were blind, deaf, and intellectually disabled. Despite the limitations of these categories, they are used throughout the thesis as shorthand descriptors of the children found in each type of setting.

A review of the existing literature in Chapter Three reveals the absence of any published research on the experiences of Jordanian parents of young disabled children with regard to their communication with service providers, their access to support and services, their needs, and their well-being. Therefore, there is a need to investigate this phenomenon within a Jordanian cultural context. The specific aims of this study are outlined below.

1:2 Research aims

In Jordan, as in many other developing countries, government officials and health care practitioners are becoming increasingly aware of the need for young children with disabilities to have access to high-quality early intervention programs. However, only a limited amount of research has been carried out on the provision of services for young disabled children and their families in such countries. Thus, this study intends to generate knowledge and promote understanding of the strengths and weaknesses of pre-school provision for disabled children in Jordan as seen from parents' perspectives. Additionally, this will be the first study focusing on parents' experiences of raising disabled children and the impact that disability can have on Jordanian families. The purposes of this qualitative research are:

- To explore experiences of parenting children with disabilities in Jordan.
- To investigate the current system of services offered to young children with disabilities and their parents.
- To understand the support systems used by disabled children and their parents.

- To identify the challenges that parents face in everyday life and the strategies they employ to manage their situations.
- To investigate communication between health care professionals and parents of children with disabilities, particularly during the diagnostic process, and its effect on parents.
- To address parental suggestions for improving the provision of special education services for young disabled children.

1:3 Research questions

This study addresses the following research questions:

- What are Jordanian parents' experiences of the services provided for young children with disabilities, beginning from the point at which their children's disabilities were first recognised?
- How do parents of young children with disabilities in Jordan perceive the services provided to them and their children?
- What types and levels of support are available for young children with disabilities and their parents in Jordan?
- How do Jordanian parents of young children with disabilities get involved in their children's education? What do parents perceive as barriers to involvement?
- What are the principal challenges facing parents of young children with disabilities in Jordan?
- How do parents of young children with disabilities in Jordan manage to deal with their responsibilities?

- In what ways do parents of young children with disabilities in Jordan feel that early intervention programmes and other related services could more effectively serve their children and improve their quality of life?

1:4 Contribution to existing literature

This study contributes to the existing body of literature by examining Jordanian parents' perspectives on parenting disabled children, and on how children with disabilities and their parents receive services from the time at which disability is first recognised. As the existing literature contains no previous qualitative studies of parenting children with disabilities in Jordan, this research will fill a significant gap. Moreover, I hope that the findings of this study will open the door for future studies to analyse the challenges that parents face in specific cultural contexts – Jordanian or otherwise – and effective methods of meeting their needs.

To date, very little research exists about the subjective experiences or perceived support needs of this population, which is typically served by the preschool provision system. This study provides information for professionals involved in delivering services to young children with disabilities and for professionals who provide support for families of disabled children. Health care practitioners can also use this information to maintain active interaction with disabled children and their families. Moreover, the results of this research can be applied to encourage policy-makers and the general public to support services for young children with disabilities in Jordan.

To the best of my knowledge, no qualitative research involving parents of children with disabilities has been conducted in Jordan. This was confirmed during the processes of recruiting study participants and collecting data collection for this study,

which used qualitative research methodology to explore this area and address the research questions set out above. Therefore, this study also provides methodological value by demonstrating the feasibility of an approach about which many gatekeepers appeared sceptical and very few Jordanian researchers employ, even in other areas of social inquiry.

1:5 Chapter organisation

This report is divided into nine separate chapters. Chapter One introduces the topic of the study, its aims and questions, and its contribution to existing knowledge, and describes the content of each chapter.

Chapter Two provides background about Jordan. A profile of the country is provided, including statistical data, information on Jordan's general educational system, and a review of educational services at the pre-school level. Issues of disability, family systems and Islamic perspectives on disability are also discussed.

Chapter Three reviews the literature related to the research topic, discusses the theoretical models of disability, and provides an overview of early intervention programmes for young children with disabilities. The literature included in the review relates to the delivery of services, being a parent of a disabled child, and parental perspectives on the services offered to disabled children and their families.

Chapter Four focuses on the methodology of the study. This chapter examines qualitative design and the processes of gaining access to and recruiting participants, interviewing parents and analysing data.

The results of the study are discussed in four chapters. Chapter Five analyses parental experiences of health care services, while Chapter Six discusses access to special education services and support. Chapter Seven examines kindergartens for children with disabilities, and Chapter Eight highlights the experiences of Jordanian parents of disabled children.

Chapter Nine summarises the main results of the study and makes recommendations from parents. Implications from this study are outlined and areas for potential future research are identified.

Chapter 2: Overview of special education services and cultural context in Jordan

2:1 Introduction

This chapter provides a basic overview of educational and special education services in a Jordanian cultural context. Beginning with a general background on the country of Jordan, the chapter then reviews Jordan's general education system at the preschool level. A discussion of special education services and legislation in Jordan follows, as well as an examination of the roles of relevant official bodies. The last section of the chapter looks at typical Jordanian family structure and analyses Islamic views of people with disabilities.

2:2 Background

Jordan – officially known as the Hashemite Kingdom of Jordan (HKJ) since its establishment in 1921 – is a small developing country located in the heart of the Middle East (figure 1). It is one of the Arabian countries and has a land area of 88,778 square kilometres. Amman is the capital city of Jordan, and is home to 38.7% of the country's total population (General Statistics Department (GSD), 2010).

According to the figures published by the GSD (2011), Jordan has a population of approximately 6.2 million, of whom roughly 3.2 million are male, and 3 million are female. 59.44% of the population are between 15 and 64 years old; 37.32% are between 0 and 14 years old; and 3.3% are over 65 years old. The average number of children per family is 5.4 (GSD, 2011).

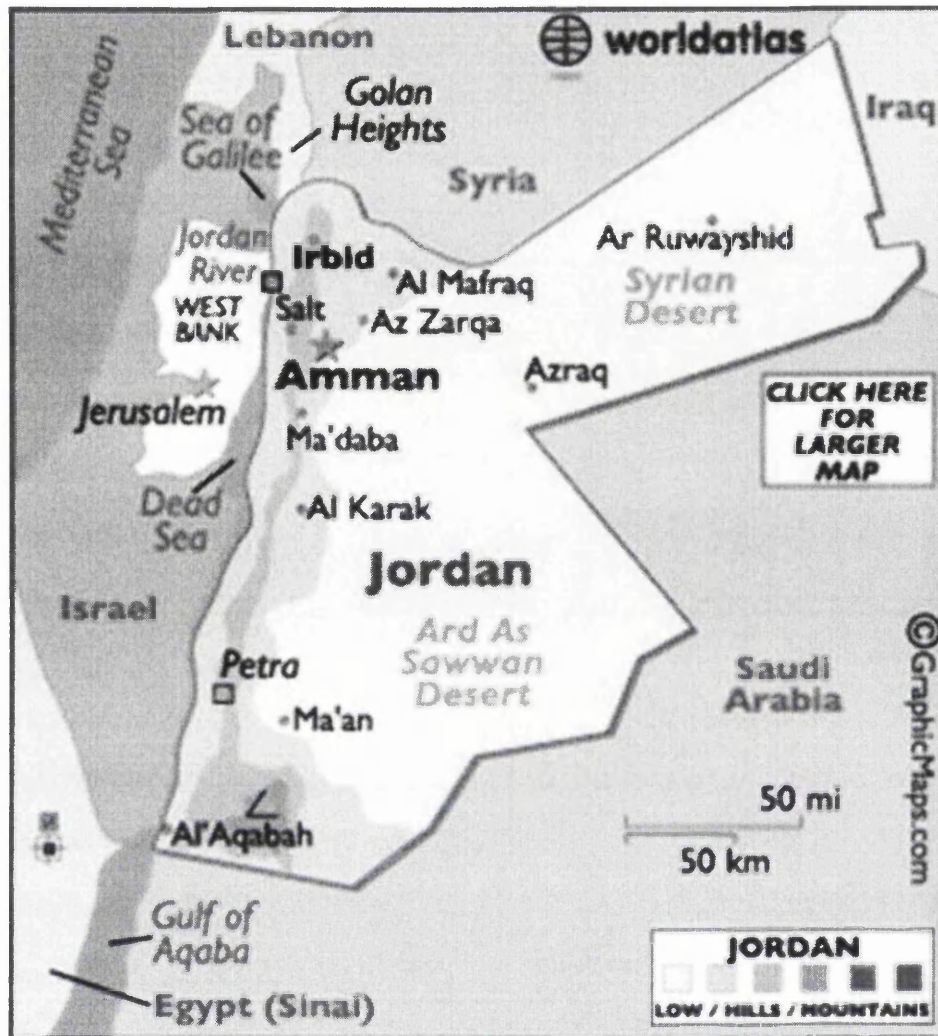


Figure (1): Jordan political map¹

The main religion in Jordan is Islam: 92% of the population are Muslims, 4% are Christian and 4% embrace other beliefs. Relationships between Jordanian people and other indigenous tribes are governed by Islamic principles (Turmusani, 2003). Although Arabic is the official language of Jordan, English is taught as a second language and is widely spoken throughout the country.

¹ Source: <http://www.worldatlas.com/webimage/countrys/asia/jo.htm>

2:3 Educational system

Jordan's first official educational government institution, the Counsel for Education, was established in 1923, followed by the establishment of the Ministry of Education (MoE) in 1940 (MoE, 2010). The main duties of the MoE, as defined by the Education Law 3, are: *“establishing public education institutions and administering them; supervising private education institutions; providing appropriate school buildings; encouraging students activities and providing them with counselling and health care; encouraging scientific research; strengthening educational links between Jordan and other countries; establishing adult education centres and reinforcing relationships with the community (UNESCO, 2011).”*

The Jordanian government views investing in education as the best way to achieve economic and social development. However, the limited nature of Jordan's natural economic resources has driven the government's focus toward human resources. From 1993 to 1997, for example, education initiatives in Jordan concentrated on the continued improvement of preschool programmes and the quality of compulsory education, as well as the improvement of teachers' competencies through providing appropriate skills training and equipping classrooms with essential educational aids. The government also modified standardised testing based on American standardised testing methods (MoE, 2004).

There are three types of schools in Jordan, all of which are supervised by the MoE: governmental schools, private schools and United Nations Relief and Works Agency (UNRWA) schools. In the 2007/2008 academic year, 1,598,211 students were enrolled in Jordanian schools (table 1), and 89,512 teachers (MoE, 2008) were

employed by Jordanian schools. Approximately one-third of the Jordanian population is enrolled or occupationally involved in education.

| The number of schools | Managed by |
|------------------------------|---------------------------------|
| 1108717 | Ministry of education |
| 345823 | Private sector |
| 125544 | UNRWA |
| 18127 | Other governmental institutions |
| 1,598,211 | Total |

Table 1: Number of students according to the school authority

Jordanian educational ladder can be divided into three levels, as shown in Table 2:

| Level | Ages | Tuition | Option |
|--------------|-------------|------------------------|----------------|
| Preschool | 4 to 6 | Fees required | Not compulsory |
| Primary | 6 to 16 | Free in public schools | Compulsory |
| Secondary | 16 to 18 | Free in public schools | Not compulsory |

Table 2: Jordanian educational levels

With regard to higher education, Jordan's first institution for higher education was established in Amman in 1958. Its aim was to prepare teachers to work in the MoE schools. Following this, many teachers' colleges were established in order to meet a growing demand for teachers. Jordan's first public university, the University of Jordan, was founded in 1962, followed by the creation of other universities throughout the country – including Jordan's first private university, Amman University, which was established in 1990.

Nowadays, Jordan has ten public universities and sixteen private universities supervised by the Ministry of Higher Education (MoHE). All of these universities offer bachelor's degrees, but only a few of them award masters and doctorate degrees as well (MoHE, 2010).

However, a history of war and conflict that includes over 60 years of Arab-Israeli conflict, the Gulf Wars, and the Arab Spring has negatively affected the economic and educational situation in Jordan. From 1947 to the present day, Jordan has hosted refugees from neighbouring countries affected by these events, such as Palestine, Iraq, and Syria. These immigrants are fully integrated into educational institutions, thus reducing the Jordanian government's ability to create an adequate quantity of schools, provide necessary educational resources and ensure that education meets a certain standard of quality (Sultana, 2008).

2:3:1 Early childhood education in Jordan

Early childhood education in Jordan begins at the preschool level. Usually, preschool children are taught in kindergarten settings; these kindergartens cater for children between four and six years old, but most children can enter kindergarten when they reach three years and eight months of age. At the preschool level, a school day lasts five hours, and students attend school five days a week for 35 weeks per year (UNESCO, 2007). The general objective of Jordanian preschools is to provide a suitable climate in which children can develop their intellectual, social, physical, spiritual/religious and emotional skills and abilities (MoE, 2010) in order to transition smoothly through all stages of education.

It is estimated that about 25% of first-grade students in Jordan have attended some kind of preschool programme (Al-Sa'd, 2007). The enrolment rate of children in Jordanian kindergartens is generally higher than the average enrolment rate for other Arab countries. Although approximately 77% of preschool programmes in Jordan are run by the private sector (UNESCO, 2007), which is considered the major provider of kindergarten services in Jordan, all preschool institutions are supervised by the MoE. Recently, the MoE created more than one hundred kindergartens in areas where the private sector had not previously established kindergarten facilities. However, most Jordanian kindergartens are converted residential properties and are rented facilities; as a result, they are often unable to deliver sufficient educational services for young children.

To promote the improvement of early childhood education, in 1999 Her Majesty Queen Rania Al-Abdullah created a team of professionals who had experience with young children to develop a strategy for a National Early Childhood Development. The strategy concentrated on children from birth to nine years of age (Roggemann and Shukri, 2009) and had among its aims the following: to increase four- to six-year-old children's enrolment in kindergartens by up to 35% before 2005; to develop and improve the quality of services in kindergartens; and to provide equal opportunities for all children in different geographical areas (Queen Rania's office, 2000).

Further efforts were made toward improving the quality of Jordanian education with the commencement of the Education Reform for the Knowledge Economy (ERfKE) Project in July 2003. Funded by the United States Agency for International Development (USAID), this project focused on supporting Jordanian governmental

education reforms through altering the educational system, primarily at the early childhood, basic, and secondary levels. The ERfKE project lasted for five years and had four major components: establishing a kindergarten curriculum, licensing standards and a standard means of assessing learning readiness; developing training and occupational standards for kindergarten teachers and administrators; increasing educational access for the poor by creating public kindergartens; and providing education for parents to increase their understanding of the importance of early childhood experiences and awareness of their roles as their children's first educators (Kaga, 2007).

Through collaborations between governmental institutions, international organisations and the private sector, the Jordanian government has been taking effective measures to improve the services provided for preschool children and to reform early childhood educational systems. However, substantial challenges still remain in this area, such as: establishing new kindergartens in different areas; refurbishing and renovating current kindergartens; increasing teachers' skills and competencies; encouraging enrolment; increasing parental participation in children's education; and integrating disabled preschool children in normal kindergartens.

2:4 Special education in Jordan

Services for children with disabilities commenced in Jordan by the middle of 19th century by some local churches and concentrated on visible disabilities such as physical and sensory disabilities (Hadidi, 1998). Jordan's first official special-needs educational institutions were created in the late 1960s to provide services for deaf, blind and intellectually disabled students.

The Higher Council for the Affairs of Persons with Disability (HCAPD) estimates the number of people with special needs in Jordan at 44,366 (HCAPD, 2010). Table 3 shows the number and percentage of disabled males and females in Jordan based on this estimate:

| Gender | Number | Percentage |
|---------|--------|------------|
| Males | 27620 | 62% |
| Females | 16746 | 38% |
| Total | 44366 | 100% |

Table 3: Number and percentage of disabled people in Jordan

It is worth noting that one of the main challenges facing disability-related policies and intervention in Jordan is the unreliability of information, especially with regard to the magnitude of the problem. While the World Health Organisation (WHO) estimates the percentage of disability in any population to be 7-10%, the Ministry of Social Development (MoSD) reports that 12.6% of the population are disabled, and the World Bank reports that there are at least 196,100 disabled persons in Jordan (World Bank, 2005); there is a significant discrepancy between these and HCAPD's figures. Hadidi (1998) and Turmusani (1999) indicated that these figures are inaccurate due to the fact that the disability considered as a stigma and people tend to not provide precise data where socio-cultural perceptions play its role in defining disabled people. Furthermore, based on a personal communication with an official employee working on statistics projects, It could be argued that people respond to the governmental surveys, which aim to measure the prevalence of disability, according to their perception of the purposes of these surveys. If they believe that the aim of the survey is to provide them with financial assistance, they are more likely to react faithfully to the survey and vice versa.

The early 1980s saw the beginning of Community-Based Rehabilitation (CBR) projects in Jordan. CBR aims to form positive attitudes about disability and to enhance the quality of life of disabled people and their families by developing equality and integration opportunities at low cost. This is ideally achieved by involving disabled persons, their families and their communities in the provision of services, with CBR specialists offering support and guidance.

In Jordan, services for disabled people are provided by governmental institutions and nongovernmental institutions (these include private institutions, voluntary associations, and international organizations). According to HCAPD (2009), there are 264 associations, centres and schools serving disabled people in Jordan, 37% of which are in Amman. Generally, these institutions offer one or more of the following services: assessment, education, rehabilitation, accommodation, learning courses, physiotherapy, speech therapy, early intervention, physical therapy, transportation, or other help.

2:4:1 Disability-related legislation in Jordan

The development of disability-related legislation in Jordan was greatly influenced by the designation of 1981 as a universally significant year for people with special needs and by the demands of parents of disabled children. Under the supervision of the MoSD and with the support of Prince Ra'ad Bin Zaid, the Law for the Welfare of Disabled People was created in 1989 and approved in 1993 (No. 12 for the year 1993). This law guaranteed the rights of disabled people, including the right to integration through the receipt of appropriate services (Turmusani, 1999, 2003); additionally, the National Council for the Affair of Disabled Persons was established to implement this law.

Since then, the Law for the Welfare of Disabled People has met with a variety of criticisms. For example, being under the MoSD's jurisdiction may restrict the law's ability to actually allow disabled people to participate in making decisions. The law is also perceived as providing welfare for, rather than enforcing the rights of, disabled people (Turmusani, 1999).

In addition to this law, Jordan has ratified two international conventions and one Arabian convention regarding the rights of disabled people, namely:

- The International Labour Organization (ILO) Vocational Rehabilitation and Employment (Disabled Persons) Convention (1983).
- The Arab Agreement on the Rehabilitation and Employment of the Disabled (1993).
- The United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol (2006).

These conventions address disabled persons' rights to equal opportunities, particularly with regard to integrated education, a high standard of health care, and inclusive and safe employment (United Nations, 2009).

Given its limitations, as well as the creation of the above conventions, the Law for the Welfare of Disabled People was replaced in 2007 by the Law on the Rights of Persons with Disabilities (No. 31 for the year 2007). Article 2 of this law classifies a disabled person as

"Any person suffering from a permanent, partial or total impairment affecting any of his/her senses, or his/her physical, psychological or mental capabilities, to an extent that undermines his/her ability to learn, work, or be rehabilitated, and in a way which renders him/her unable to meet her/his normal day-to-day requirements under circumstances similar to those of nondisabled persons". (HCAPD, 2007)

The new law clearly identifies the roles of different disability-related institutions and disabled persons' rights to the following:

- health care
- education and higher education
- vocational training and labour
- social protection and institutional care
- accessible environments
- customs and tax exemptions
- public and political life
- sport, culture and recreation
- legislation.

Among the Arab nations, Jordan has been the leader in enacting laws geared toward disabled people's rights as the result of being influenced by American legislation (Rutherford, 2007). However, while the aforementioned new laws set out the rights of disabled people and promote many practical methods of achieving these aims, obstacles such as poor communication and coordination between different agencies and sectors may hinder effective implementation of these laws.

2:4:2 Jordanian institutions involved in students' disability issues

In Jordan, there are several governmental institutions that offer services for children or students with disabilities. The following section briefly addresses the essential roles of these institutions.

The MoE

Over the last two decades, the MoE managed to significantly improve the provision of services for students with disabilities. One MoE plan (1998-2002) focused on enhancing the education of children with special needs by establishing a Directorate of Special Education within the MoE. This Directorate directly supervises and monitors the four types of educational programmes offered to disabled students, which are:

1. Learning difficulty programmes: the MoE supplies attached resources classes for children who have impaired language and/or mathematical skills. Over 12,000 students between eight and 12 years old were enrolled in these classes as of the beginning of the 2007/2008 academic year. However, only students from grade two to grade six are eligible for these classes.
2. Hearing impairment programmes: the MoE supervises 10 specialised schools for children with hearing disabilities. These schools serve more than 700 students from preschool to sixth grade.
3. Blindness programmes: two special schools provide services for visually impaired children. 27 students from first to sixth grade are served by the first school, which has a dormitory for students who come from outside Amman, and the second school serves students from seventh to twelfth grade. As of the beginning of the 2007/2008 academic year, 483 students were graduated from these schools.
4. Intellectual disability programme: there are five annexed classrooms within the regular schools distributed in Amman. These classes serve 35-40 students with intellectual disability (MoE, 2008).

The MoSD

The MoSD is the traditional service provider for children with disabilities in Jordan. Since the MoE took over disability programmes, the MoSD has been responsible for the following within its directorate of the Person with Disabilities Affairs: supervising care, rehabilitation, training, recreation, and residential programmes for disabled people; setting up CBR programmes throughout the country in coordination with the MoH and HCAPD; and officially registering and licensing institutions (MoSD, 2010).

The MoSD also provides financial aid for disabled people or their families, but few people are actually eligible for this support; eligibility is determined on a case-by-case basis by the National Aid Foundation.

The MoH

The MoH aims to reduce the detrimental effects of disabilities through supplying vaccinations, health surveys and nutritional advice for newborns. Through its public health centres, the MoH also provides diagnosis and early identification services, treatment, physiotherapy, and physical therapy. Additionally, the MoH runs large-scale programmes to increase public awareness regarding disabilities.

One of its institutions, the Centre for Early Detection of Disabilities (CEDD) – established in 1990 in coordination with the MoSD – is, as the name suggests, focused on the early detection of disabilities in children. Most disabled children are required to have an assessment report from this centre in order to access special educational provisions and support.

The HCAPD

Created by the Law on the Rights of Persons with Disabilities in 2007, the HCAPD is the primary institutional umbrella that monitors the implementation of disabled persons' rights. Its main roles are to form national policies, enact legislation, and coordinate with different parties in order to support, promote and protect disabled persons' rights. To fulfil these tasks, an eight-year plan funded by 65 million JD was established by His Majesty King Abdullah II. This plan, known as the National Strategy for People with Disabilities, focused on improving the quality of life of disabled people, increasing social awareness of disabilities, maintaining rights to equality and comprehensive health care, and facilitating easier access to high-quality integrated services.

The National Strategy and the HCAPD have led to improvements in many areas, such as:

- legislation
- an increase in the number of institutions serving disabled people
- increased accessibility in public areas
- free health care insurance
- and the exemption of devices, educational aids and equipment used in disability services from duties and import taxes.

However, Jordan's special education services still require further attention. Higher education services, for instance, are not widely accessible to students with special needs (Sultana, 2008). Additionally, these services are mainly offered in Amman and are not delivered within an integrated framework.

2:5 Preschool services for disabled children in Jordan

Developmentally speaking, a disabled child's first years are the most important times of his/her life, as detecting a disability at this stage can lessen its effects. As a result, Jordan's has several institutions with a special focus on early-years rehabilitative and educational services for disabled children (Akrouk, 2008):

- The Cerebral Palsy Foundation: this institution has many branches throughout the country and offers numerous kinds of services for children with cerebral palsy, such as diagnosis, remediation, physiotherapy, physical therapy, and essential aids to help with movement.
- Institute for Family Health: the Institute provides detection, screening, and rehabilitation services to children with different types of disabilities, including intellectual disabilities and learning difficulties.
- CBR programmes: as mentioned earlier, these programmes, offered by both governmental and nongovernmental institutions, aim to enhance the quality of life for people with disabilities and their families, within general community development. There are 23 CBR programmes in Jordan.
- Al Bashir Hospital: its rehabilitation department offers occupational therapy for children with different kinds of physical disabilities.
- Portage programmes: adopted from the USA, Portage provides assessment and training services and parenting classes to mothers of children up to the age of nine with mild to moderate intellectual and physical disabilities.
- Al Hussein Society Programmes: this society's early intervention department offers rehabilitation services for children under the age of six with physical disabilities (Akrouk, 2008).

In addition to the above institutions and programmes, there are three other kinds of kindergartens for young disabled children in Jordan. The MoSD runs a few kindergartens for intellectually disabled children, while the MoE runs a kindergarten for hearing-impaired children. As alluded to earlier, the private sector and voluntary sector run a number of kindergartens for hearing-impaired, visually impaired and intellectually disabled children. Most special education services offered by preschools do not include ongoing services for parents, and are of varying quality.

2:6 Jordanian families and Islamic perspectives

Family is the core component of the Jordanian community. The basic Jordanian family unit usually consists of a father, a mother, and their children, and marriage is considered the only legitimate basis on which to start a family. The father is the primary authority in the family and has the final say on most family decisions. Most Jordanian families live near their extended family members, such as grandparents, and share their economic and social duties. The oldest daughter in the family may be responsible for helping her mother with duties such as cleaning the house and taking care of the younger children. Unlike in Western countries, often unmarried people do still live in their parents' homes until they get married.

One of the main functions of the family in Jordan is producing and caring for children. While the primary responsibility of childcare lies with the mother, especially with female and/or very young children, the father is responsible for the financial well-being of the children and family (Sultana, 2008). Jordanian families place a high value on their children's rights to safety, proper nutrition, education, equality, and integration. They are also keen to educate their children in the traditions and precepts of Islam by instilling in them, at the bare minimum, an elementary

knowledge of the Qur'an (the holy book of Islam) and Hadith (the Prophet Mohammed's sayings and deeds).

However, the economic, social, and political conditions in Jordan and the Middle East have given rise to changes in the structure and functions of the traditional Jordanian family. Although rural and Bedouin families still favour an extended family structure, a trend toward nuclear families has emerged in major cities. Parents' roles within the family have also been altered by the changing incomes and educational levels of both mothers and fathers.

As mentioned earlier, the majority of Jordanian residents are Muslim. Understanding Islamic perspectives on disabilities may therefore help in analysing the experiences of the participants in this study. Ideally, Muslims are meant to carry out their daily activities according to their understanding of the Qur'an and Hadith, which are the main sources of Islamic legislation. The Qur'an is the prime text of Islam and is supported by Hadith, which aids in the explanation and interpretation of the Qur'an.

The term 'Muslim' means accepting, surrendering to, or submitting to our Lord (Allah) (Hasnain *et al.*, 2008). In this context, everything that happens is determined by the will of Allah, whose acts must not be questioned – although the acts of people can and will be questioned. The fates and destinies of people are governed by Allah, who sometimes tests people in different ways. These tests can be administered by putting people in positive or negative situations:

We are putting all of you to a test by passing you through bad and good conditions, and finally you shall return to Us. [35]²

² Holy Qur'an, interpretation of verses 35, chapter 21 AL-ANBIYA' (Malik 2007, p.137).

The best way to pass these tests is by praising Allah for his will, which ensures a greater reward in the afterlife. Additionally, Islam does not encourage Muslims to be passive. Both the Qur'an and Hadith encourage Muslims to actively participate in the world while trusting Allah.

The Islamic perception of disability can be seen in the following verse:

*O mankind! We created you from a single pair of a male and a female, and made you into nations and tribes that you might get to know one another. Surely the noblest of you in the sight of Allah is he who is the most righteous. Allah is All-Knowledgeable, All-Aware.*³

This verse mentions Islam's core principles of brotherhood, justice, and equality. While disability and chronic illness are acknowledged in the Qur'an, this verse (and others) suggest that acts of discrimination between people are against Allah's teachings. In a divine sense, people are not judged by their appearance, abilities, or any abnormalities in their development, but rather by their piety and good deeds. The physical, racial, and material differences between people or groups are not important in Islam.

A number of verses and stories in the Qur'an encourage Muslims to care for disabled people and treat them fairly and equally. One such story involves the prophet Mohammed and one of his companions, Abdullah Ibn Umme Maktum. Abdullah, who was visually impaired, sat with the prophet Mohammed while he (Mohammed) was attempting to convert the leaders of the Quraish tribe to Islam. Mohammed

³ Holy Qur'an, interpretation of verses 13, chapter 49 Al-Hujurat (Malik, 2007, p.265)

neglected Abdullah at the time, but was later admonished by Allah for this ignorance:

He (the Prophet) frowned and turned away [1] when there came to him the blind man (Ibn Umme Maktum, who came to the Prophet and interrupted his conversation with the chiefs of Mecca). [2] How could you tell? He might have sought to purify himself [3] or become reminded and might have benefited from Our reminder. [4] As for him who is indifferent, [5] to whom you were attending; [6] you will not be held responsible if he would not purify himself. [7] Yet to him who came to you with zeal on his own [8] and with fear of Allah in his heart, [9] you gave no heed. [10] It should not be so! Indeed, this is but an admonition; [11] let him who wants, accept it. [12] It is written in scrolls, which are honoured, [13] exalted, purified, [14] and which remain in the hands of scribes, [15] who are noble and virtuous. [16]⁴

Islamic legislation stipulates the necessity of providing a safe and stable living environment for disabled people; the responsibility to care for the disabled lies with the entire Muslim community (Alkadomi, 2004; Banza and Hatab, 2005; Hasnain *et al.*, 2008). This care includes teaching them about ethical principles and acts of worship within an integrated framework and taking their condition into account when assessing their fulfilment of their religious duties. Alkadomi's (2004) discussion of the rights of the disabled in the Islamic law states that each person in every Islamic community must meet certain needs to survive and that these needs fluctuate based on place and time. If a person is not able to meet these basic needs due to illness or impairment, the local Islamic government should provide help and support to allow that person to enjoy a reasonable standard of living. This support is mainly covered by the Islamic state treasury and provided to any disabled person in the Islamic community, regardless of his/her nationality or religion (Alkadomi, 2004). Further, the Hadith relates many incidents of the prophet Mohammed encouraging Muslims

⁴Holy Qur'an, interpretation of verses 1-16, chapter Abasa 80 (Malik, 2007, p.265).

to look after the disadvantaged and facilitating the process of mainstreaming them in their communities (Banza and Hatab, 2005).

Although disability can be seen as an act of Allah, the significance of this act can be interpreted in different ways. While some Muslims may perceive disability as a blessing from Allah to test their acceptance of his will, others may view it as a punishment. Both understandings could lead to an unwillingness to seek treatment or support (Kramer-Roy, 2007). However, these consequences are not compatible with the Qur'an and Hadith (Banza and Hatab, 2005). For example, the prophet Mohammed says:

'Allah has sent down both the disease and the cure, and He has appointed a cure for every disease, so treat yourselves medically, but use nothing unlawful'⁵

Although Islam encourages communities to protect and care for the needy within an inclusive framework, in many Muslim societies people with disabilities and their families experience a lack of support and feelings of isolation, stigma and blame (Crabtree, 2007; Hasnain *et al.*, 2008; Kramer-Roy, 2007).

2:7 Summary and Conclusions

In collaboration with the private sector and international organisations, the Jordanian government has made a mostly successful effort to improve education. Student enrolment rates and the number of schools have increased at the primary, secondary and higher education levels.

⁵Sunan Abu-Dawud. Book 28, Number 3865.

Disability rights and special education have also improved in Jordan, with governmental and nongovernmental institutions increasing the availability, accessibility, acceptability and quality of services in these areas. However, obstacles to the improvement of special education provision in Jordan still remain, such as funding shortages, negative attitudes and the discrepancy between the number of services provided and the number of disabled people living in Jordan.

Attitudes toward childcare are shaped by the traditional Jordanian family structure, which focuses heavily on the welfare of multiple children, and by interpretations of Islamic values. Although Islam insists on equality between people regardless of their physical characteristics, these aspects of traditional Islamic perception are not necessarily adhered to in most Muslim communities.

CHAPTER 3: Literature review

3.1 Introduction

In order to provide a well-organised review of the relevant literature in this field, this chapter has been divided into five sections. The first section begins by providing a brief overview of the prevailing theories regarding disability within the medical and social models. This is followed by a section that outlines the range of preschool provision for children with disabilities, and discusses the importance of, early intervention and early identification.

The third section examines the existing literature on the delivery of services to young disabled children with a special focus on the family-centred model, which involves parents of disabled children in the service delivery process.

The fourth section discusses the experience of being a parent of a disabled child in relation to the following topics: communication between health care practitioners and parents during the diagnosis of a disability; reactions to the identification of a disability; parental needs; challenges and burdens created or affected by disability; and coping strategies used by parents.

The last section considers parental perceptions of the services available to children with disabilities and their families. To give a thorough review of the literature on parental experiences of service delivery and caring for disabled children, these studies have been organised chronologically based on certain selected themes.

3.2 Theoretical models of disability

Models of disability provide frameworks for practitioners to understand the ways in which disabled people experience disability, and to explore the effects of disability on disabled people and their families. These models may help us to understand different aspects of life for disabled children and their parents (Brett, 2002). Over the last few decades, a number of models have been used to approach the issue of disability. The following two sections discuss the most commonly and most frequently used of these models, namely the medical model and the social model. Both models contribute to a greater understanding of the lives of children with disabilities and their families.

3.2.1 Medical model

The medical model of disability focuses on the limitations imposed by a disability and its effects on the disabled person. In this model, disabled people are seen as being sick, with conditions requiring care, support, and treatment (Grewal *et al.*, 2002; Scullion, 2010; Smith *et al.*, 2011). Viewed in this way, disability is an internal and individual problem for the disabled person that calls for medical attention and cure. This model is called the ‘individual model’ by some researchers (Beckett and Wrighton, 2000; Brett, 2002) as it supports the idea that the individual should adapt to the structure of society. Generally, this idea portrays disabled children as being flexible and able to change and society as unalterable. According to this model, a disabled person who fails to adapt to his or her society would be considered to not belong to that society (Brett, 2002).

Researchers argue that this perspective of disability may negatively affect disabled people's senses of identity, as they may internalise these negative beliefs and feel that their problems and difficulties come from being abnormal (Campbell and Oliver, 1996; Dowling and Dolan, 2001; Smith *et al.*, 2011). The professionals who adopt this model tend to view children with disabilities as impaired individuals first and children second, which restricts the abilities of disabled children and their parents to participate in decision-making and negotiating services, and also limits their involvement in intervention programmes. Case (2000) reports that this mindset illustrates the inequality of relationships between parents of children with disabilities and healthcare professionals; parents are simply information providers for professionals, who as experts are responsible for intervening with and caring for disabled children.

The medical view of disability also creates negative attitudes toward disabled people by reinforcing the continuous dependency of disabled people on medical professionals. These professionals mainly focus on seeking causes and treatments for the symptoms of disability (Scullion, 2010), rather than on meeting the special needs of disabled children and their families. Consequently, disabled children are vulnerable to discrimination, prejudice, ignorance, stigmatisation and isolation (Brett, 2002; Campbell and Oliver, 1996; Case, 2000).

Undoubtedly, any person can be affected either directly or indirectly by environmental factors, which in this context include social attitudes and beliefs, available services, and economic resources. The medical model's perspective on disability may ignore the influence of environment on disabled people, and may therefore foster prejudice by judging disabled people without taking environmental

impact into account. However, total rejection of the medical model of disability may hinder the development of medical intervention and prevention programs for people with disabilities.

3.2.2 Social model

The social model of disability was created by disabled people as a rejection of the medical model's view of the individual disabled person as being responsible for handling disability and the lack of focus on environmental influences (Bricher, 2000). In contrast to the medical model, which concentrates on the functional limitations of the individual disabled person, the social model of disability transfers the focus from the individual to society as a whole and the obstacles created by social environments (Brett, 2002; Burke, 2004; Grewal *et al.*, 2002). Dowling and Dolan (2001, p.23) illustrate the social model as follows: *"being unable to walk does not, in itself, prevent an individual from going shopping, but public transport that is inaccessible to wheelchair users does. The individual is being disabled, not by their impairment, but by the failure of society to take account of and organise around difference"*.

The social model argues that the discrimination and inequality experienced by disabled people are caused by social limitations which prevent disabled people from being integrated into social activities (Scullion, 2010). This idea is supported by many researchers such as Dowling and Dolan (2001), who have discussed the inequality that disabled children and their families experience in different aspects of life such as entertainment, job opportunities, general quality of life, and finances. Brett (2002) suggests that physical and social barriers have marginalised and

oppressed disabled people and that practitioners in the field have been influenced by this view.

According to the social model, organisational and attitudinal barriers should be removed to ensure optimal mainstream services for disabled people by offering equal opportunities and access to education, employment, transport, accommodation, and recreation. The social model also promotes the active participation of children with disabilities and their parents in the planning and delivery stages of the services they require. However, although the social model of disability has significantly contributed to understanding disability, viewing disability as a purely social matter ignores the personal experiences of disabled people and their families, and prevents disabled people from freely expressing their feelings about their disabilities. Further, health conditions must be considered when addressing the issues of care and quality of life for children with severe disabilities.

3.3 An overview of preschool provision for children with disabilities

Preschool provision for children with disabilities consists of educational, medical, social and psychological services established for children who have special needs or younger children considered to be at risk of developmental problems. Since the special needs of children eventually affect all family members, particularly parents, most early intervention activities are targeted at parents. This section discusses early intervention and early identification and the impact of such programmes on disabled children and their parents.

3.3.1 What is early intervention?

Pioneering research confirms that early intervention has many benefits for disabled children and their parents. The definition of early intervention is a popular topic of discussion among researchers in this field. Early intervention programmes include activities to promote children's development and prevent developmental delays (Feldman; 2004; Smith and Dukes, 2009; Wall, 2003). Brambring *et al.* (1996) define early intervention as a supportive provision targeted at families of children with impairments or who are at risk.

Hanson and Bruder's (2001, p.48-49) broad definition of early intervention services states that such programmes consist of the following: *"Services designed to meet the developmental needs of infants and toddlers with disabilities in one or more of these developmental areas: physical, cognitive, communication, social/emotional, and adaptive. These services encompass a wide range of options and include family training, counselling, and home visits; special instruction; speech language pathology and audiology services; occupational and physical services; psychological services; service coordination; medical services; early identification; screening, and assessment; health services; social work services; vision services; assistive technology services; and transportation and related costs that enable children and families to participate in services"*.

Despite some researchers indicating that early intervention services are those services provided to disadvantaged families and their children from birth to the age of three, other researchers argue that early intervention services can continue up to the age of five years (Doyle *et al.*, 2009; Reynolds, 2000) or even eight years (Reynolds, 2004; Wall, 2003). For example, Reynolds (2004, p.16) defines early

intervention as *“the provision of educational, family, health and/or social services during any of the first eight years of life to children who are at risk of poor outcomes because they face socio-environmental disadvantages or have developmental disabilities”*.

By and large, early intervention services are delivered not only to children who have, or are at risk for, delayed development, but also to their parents, since children spend the majority of their time with their parents. Accessing early intervention programmes is seen to help special-needs children receive assessment, intervention and preventive services provided by qualified and multidisciplinary teams of providers in coordination with parents.

3.3.2 Early identification and early intervention

Early identification and early intervention are two widely used phrases in the special education field (Mathieson, 2007). Early identification aims to identify which children require special education or extra support, assesses children’s general ability levels, identifies the delay of developmental trajectories and describes the purposes of educational assessment (Jones, 2004). It must be stressed that early identification focused on identifying the best way to meet children’s needs and is not a means of sorting or labelling children (Tassnoi, 2003). Unless children’s needs have been clearly identified, they will not be able to access appropriate curricula or be enrolled in adequate early intervention programmes.

Early identification may also help families of disabled children by alleviating parental stress and grief (Tattersall and Young, 2006). In Fitzpatrick *et al*’s study (2007), early identification of hearing loss increased children’s chances of improving

their language and speech skills and access to rehabilitation services, and also provided facilitation for families to accept their children's hearing loss.

In order for early intervention programmes to run effectively, it is necessary to determine who is eligible for such services, which can be achieved in part by identifying children at risk for developmental delays. This early identification may eventually be followed by early intervention. As a specific curriculum cannot be prepared without an understanding of children's abilities, children eligible for early intervention programmes should be identified before such programmes are planned.

3.3.3 The importance of early intervention

Research in the field of special education, particularly with regard to young children, suggests that the earliest years are the most significant developmental period in terms of vulnerability (Carpenter, 2005; Doyle *et al.*, 2009; Reynolds, 2004; Upshur *et al.*, 2009; Welshman, 2008). The importance of environmental influences on children's development shapes the primary source of early intervention (Nores and Barnet, 2009). Welshman (2008) mentions that experts' changing perceptions of children's intellectual development, particularly in the 1950s and 1960s, led researchers to focus more on the early years of development. Research has also revealed that experiences of infants and young children in the early years underpin long-term cognitive, mental health and physical development (Karoely *et al.*, 1998).

21st-century research provides considerable evidence of the positive effects of early intervention programmes on children's development (Hanson and Bruder, 2001; Reynolds and Temple, 2005; Shonkoff and Meisels, 2000). Roffey (2001) suggests two factors accounting for the significance of early intervention programmes. The

first is that they promote development, since children are very educable and sensitive in their early years. The second is that they maintain children's self-esteem by preventing children from being isolated or negatively protected and giving children opportunities to participate in shared activities. Early intervention programmes alter children's development trajectories (cognition, behaviour, emotion, health and schooling), and prevent developmental delays in the future (Doyle *et al.*, 2009; Kagitcibasi *et al.*, 2001; Nores and Barnett, 2009). In addition, Reynolds (2000) suggests that two other beneficial outcomes of early intervention are social adjustment and motivational advantage in classroom settings.

As parents rarely anticipate that their children will be disabled or have serious health conditions, diagnoses of disabilities will create crises at any stage – early or later – in children's development. Parents frequently experience denial, hopelessness, stress, and trauma (Dale, 1996; Heiman, 2002; Russ *et al.*, 2004; Wall, 2003). The provision of early intervention programmes appears to help to sustain parents at this difficult time (Carpenter, 2005, 2007; Kagitcibasi *et al.*, 2001). Emotional support and information on, for example, educational options and support resources are provided by specialists to enable parents to deal with their children (Guralnick, 1997; Roffey, 2001).

Wilson (2002) points out other beneficial outcomes for disabled children's families such as enhanced mother-child interaction (Benasich *et al.*, 1992), increased attendance in school and/ or work, improving the maternal skills of teenage mothers and decreasing stress for parents. Benasich *et al.* (1992, p.313) advocate the uses of early intervention programmes as follows: "*intervention programmes, with little tailoring, could be vehicles for enhancing maternal competence, self-esteem, as well*

as parental efficiency and child competence". Further, in Bailey *et al*'s (2004a) longitudinal study, most parents acknowledged that early intervention had made a significant impact on their families; as a result of these effects, they became hopeful about their children's futures and learnt how to care for their disabled children.

By 1997, some scholars began to discuss early childhood programmes in terms of their economic outcomes and the theme of 'investing in young children' was emerging (Brooks *et al.*, 2000). Many concluded that investing early in disabled children led to greater and longer-lasting benefits (Doyle *et al.*, 2009). For example, if proper preventative or remedial programmes were made available to visually impaired children in the early years, high-priced equipment and additional staff would not be necessary in the future, thus achieving economic saving. Karoly *et al*'s (1998) cost-benefit analysis of the Perry Preschool Programme suggested that the programme reduced the requirement for special education, increased employment (which consequently increased collected tax revenue), reduced the period of time leavers spent unemployed and in receipt of welfare benefits, and reduced the costs to the criminal justice system of dealing with offender behaviour.

Many advantages can be gained by implementing systematic early intervention programmes – not only for developmentally delayed children and children at risk, but also for their families. These benefits could include improvement in children's developmental opportunities or enhanced parental skills which will empower parents to deal with their children and meet their needs. Economic benefits such as a reduced need for special education have been seen to result from such programmes. It is worth mentioning that the benefits derived from early intervention result from mutual

influence; improvements in children's development can improve family and community life as well.

3.4 Delivering early intervention services to children with disabilities

Delivering special education services to young children with disabilities can be classified according to two different criteria. The first of these criteria is the setting where the services are delivered; these might be formal or informal locations such as centres, clinics, the children's homes, kindergartens or schools. Alternatively, services may be classified according to their target – that is, whether they are geared toward children, mothers, parents and/or families (Benasich *et al.*, 1992; Nores and Barnett, 2009). However, regardless of the classification used, delivery of special education services is influenced by several factors including the unique conditions of children with disabilities and their families, the availability of specialists, and geographic factors (Wall, 2003).

3.4.1 Delivering the services according to setting

As mentioned above, special education services can be home-based, centre-based, a combination of centre- and home-based, or hospital-based. In home-based programmes, service providers visit children's homes in order to present informational, material, and emotional support to families and encourage them to be involved in educating their disabled children (Davidson and Harrison, 1997; McWilliam and Scoot, 2001). The Portage programme is an example of a home-based service (Brue and Oakland, 2001). While the home is a suitable setting for special education, home-based services may have the effect of isolating children (Carpenter, 1997).

In centre-based programmes, parents and children receive early intervention services by going to centres and meeting the practitioners. These centres might be special centres, nurseries or kindergartens. The Abecedarian programme is an example of centre-based early intervention; in this programme, parents go with their children to special centres in order to receive a well-structured curriculum (Karoly *et al.*, 1998). However, in centre-based programmes children may not always receive adequate and appropriate attention, particularly in larger learning groups (Carpenter, 1997).

In combined centre-based and home-based programmes, parents and their children receive a mixture of both centre-based and home-based services (Karoly *et al.*, 2005). Sometimes children and their parents may go to centres to receive training in different aspects of education such as cognitive development; at other times, intervention practitioners may visit children's homes to provide other types of services.

Another type of programme for disabled children is hospital-based nursing care (Avis and Reardon, 2008). In general, children with disabilities have a higher chance of being admitted to and staying in hospital than non-disabled children (Avis and Reardon, 2008; Mahon and Kibirige, 2004). For some conditions, especially in the early years, children may require special medical care and technology which are not readily available in either their homes or educational centres, thus rendering hospitals the best setting for delivering adequate intervention services. For example, a pre-term child may need intensive care that cannot be offered either in the home or in an educational centre.

3.4.2 Delivering services according to the target group

In the past, early intervention programmes generally focused on children's development (Dale, 1996), whereas current special education services are concerned with supporting not only disabled children but their families as well (Bailey *et al.*, 1999; Carpenter, 2007; Guralnick, 2005). Early intervention practitioners focus on children with disabilities and their families, and sometimes this focus is even expanded to children's communities (Dale, 1996; Dunst, 1996).

As a result of moving from the medical model of disability to the social model of disability in the last few decades, there has been an increased understanding of the necessity of meeting the needs of families of disabled children and of encouraging them to be involved in planning, delivering, and evaluating the services they receive. The current approach to early intervention aims to put families in a position where they can control and access services themselves rather than waiting for services to be delivered (Carpenter, 1997). According to Porter (2002), the best way to meet children's needs is to consider every member of the family. Early intervention should be provided in a way that allows every member of a child's family to be integrated into daily activities (Brambring, 1996). Carpenter (2007 p.664) explains this approach thusly: *"In any individual family context, there is a unique pattern of need. Early childhood intervention services have to be prepared to meet the spectrum of need and to be equipped to recognize and respond to it. Professionals will need to work with families collaboratively and sensitively to allow them to identify their needs and to pre-empt negative effects"*.

This in turn has led to the emergence of a family-centred approach, which the early intervention field adopted in the 1990s (Espe-Sherwindt, 2008). This approach

focuses on giving families of disabled children the ability to control and manage situations through receiving information, developing skills, and using the resources that are available to them. Family-centeredness refers to “*a particular set of beliefs, principles, values and practices for supporting and strengthening family capacity to enhance and promote child development and learning*” (Dunst, 2002 p.139). This model of delivering special education services is deemed to be one of the most active and widely accepted practices in the fields of early intervention and health care (Brett, 2004; Dunst, 2002; King *et al.*, 2004; Wade *et al.*, 2007).

As the way in which services are delivered can affect their outcomes, this model of service delivery promotes partnership between parents and service providers. Parents may be enthusiastic about working with the professionals who provide services to their children (Park and Turnbull, 2001). Dunst (2002) identifies two key components of family-centred practice with regard to interactions between parents and professionals as relational and participatory behaviour. To demonstrate relational behaviour, professionals should show parents empathy, warmth, authenticity, trustworthiness, and respect. Parents’ strengths should be recognised and their opinions listened to, and professionals should take their capabilities and competencies into account. The participatory component includes offering opportunities for parents to be actively involved in the educational process and develop parental skills, and taking into account parents’ concerns and priorities (Dunst, 2002).

Dunst *et al* (2007) conducted a meta-analysis of 47 studies related to family-centred practice in terms of delivering special education services to disabled children and their families. The analysis focused on the impact of such practices on parents,

children, families, and children's behaviour and functioning. The results indicated that implementing a family-centred model was more likely to increase parental satisfaction with special education services, improve parents' abilities to achieve positive results and to evaluate services providers, and promote parental skills, families' well-being, and children's behaviour and functioning.

Further support for family-centred practice is provided by a study conducted by Wade *et al* (2007), which explores parents' experiences with the delivery of special education services. The researchers divided respondents' statements into two categories: helpful practice and unhelpful practice. Most statements in the 'helpful practice' category were found to relate to a family-centred approach. When the parents were asked what types of services they would like to receive in the future, most of them expressed their willingness to receive services that adhered to a family-centred model. Similarly, a quantitative study conducted by Whitaker (2007) argues that understanding, empathy, and a strong relationship with schools are the factors that most affect parental satisfaction with special education services.

An effective early intervention programme must consider the contexts in which the parents of disabled children live and take the complex needs of individual families into account. Practitioners should concentrate on promoting families' strengths as well as correcting their deficiencies, as parents' pre-existing skills may provide a starting point for the delivery of intervention services (Espe-Sherwindt, 2008; Wade *et al.*, 2007).

Previous studies have identified several barriers encountered by practitioners in adopting family-centred practice. These barriers include inefficient training models provided to professionals; scarcity of proper evidence based on empirical research;

and professionals' attitudes and lack of awareness regarding the effectiveness of this approach (Espe-Sherwindt, 2008; Wade *et al.*, 2007). Although the research supports the application of a family-centred model in caring for children with disabilities, non-collaborative and negative relationships between parents and professionals are still evident (Crawford and Simonoff, 2003; Dunst, 2002; Dunst *et al.*, 2007).

Family-centeredness puts parents' views and needs at the forefront in order to determine how best to meet disabled children's needs in a family context. Previous studies state that parents find a family-centred approach in which they can receive practical support, share decision-making duties with professionals, and be enabled to care for their children the most useful method of delivering special education services. Ideally, a comprehensive implementation of family-centeredness would ultimately enhance the quality of life of families of children with disabilities. However, some of these studies recruited parents from the services they used, and each parent came from a particular population and had unique characteristics; therefore, these findings cannot be generally applied.

In addition to assisting and supporting families and enabling them to deal with their children's challenges, family-centred services are also responsible for collaboratively and respectfully teaching coping skills to family members in order to increase their resilience and adaptability. As a result, parental involvement is the most influential factor in family-centred practice.

3.4.3 Parental involvement in service delivery

Due to an increased awareness of the influence that families can exert on children's development, all family members are persuaded to participate in the services

provided to their disabled children. When children's parents and families are engaged in early intervention programmes, they may receive many benefits (Bailey *et al.*, 2005; Jinnah and Walters, 2008; Kagan and Neuman, 2000; Miedel and Reynolds, 1999), such as the development of positive attitudes towards their abilities which promote family well-being. Wall (2003) points out that a strong partnership between parents and practitioners might produce positive outcomes not only for children, but also for the parents and practitioners involved. Along these lines, the Code of Practice for Special Educational Needs (Department for Education and Skills (DfES), 2001) calls for professionals to encourage parents to be involved in educating their child and working with professionals as partners. Studies in the field of healthcare support this initiative. For example, Avis and Reardon (2008) suggest that parental involvement decreases the potential for anxiety by helping parents to feel in control of their childcare. Further, encouraging parents to be involved may facilitate modern inclusive practice and establish mutually positive relationships, which in turn help schools to meet children's needs (Checker *et al.*, 2009).

The literature highlights two justifications for professionals to form partnerships with parents in the education of special-needs children. First, such partnerships help to facilitate children's transitions between the care of professionals and their families (Wall, 2003), especially with regard to daily life activities such as walking, talking and toilet training. Second, parents are experts regarding their own children's needs, as they have key information about different aspects of their children's development (Jinnah and Walters, 2008; Jones and Swain, 2001).

The involvement of parents of special-needs children in early intervention programmes has been described as "*a key to...success*" (White *et al.*, 1992, p.92). An

earlier example elucidating this statement is highlighted in Dawson and Osterling's (1997) study, wherein autistic children's parents were taught fundamental therapy techniques and collaborated with staff in the delivery of therapy. The autistic children made important progress and became more responsive to their parents than to the therapists.

In a longitudinal study conducted by Miedel and Reynolds (1999) to discover whether parental involvement influenced children's achievement in later years, the researchers interviewed 704 parents of children who had enrolled in early intervention programmes. Findings showed that when parents were highly involved in preschool and kindergarten activities, their children's achievement significantly increased, grade retention decreased, and the number of years spent in special education decreased.

Intervention programmes without a parental involvement aspect are less likely to improve the outcomes of services for children with disabilities. Mahoney and Perales (2006) tracked the motor development of 27 children with Down's syndrome and 23 children with cerebral palsy who had received early intervention services. The results revealed that the children had made no significant progress in the acquisition of motor skills as a result of the intervention services they received, which was in turn caused by the relative exclusion of parents; parents were present in only 57% of therapy sessions and were given very few suggestions by service providers.

Some researchers have established a link between parental involvement and parental satisfaction with early intervention services. For example, in a study conducted by Laws and Millward (2001), 131 parents of children with Down's syndrome in England, Wales and Northern Ireland were asked to complete a postal questionnaire.

Analysis of these questionnaires indicated that parents who expressed a fair level of satisfaction with the services they had received had higher levels of contact with classroom teachers and support staff, while dissatisfied parents had much less contact with their children's schools. The parents who had more involvement in the classroom were more satisfied with their children's education services, suggesting that one of the main predictors of parents' satisfaction with special education services is their degree of involvement.

These findings were confirmed in the United States by Bailey *et al* (2004b), who investigated experiences, interactions, and satisfaction with early intervention services and professionals from the perspective of parents whose children were enrolled in Part C early intervention programmes. Most parents were highly satisfied with many of the services; 81% of respondents reported that decisions on the services' goals were made collaboratively between them and professionals. Although 77% of respondents felt that they were involved in the decision-making process to an appropriate degree, 22% would have wanted to be more involved. Further, 88% of respondents rated their communication with professionals as excellent and good.

Jinnah and Walters' (2008) recent study explores the relationship between parental involvement and parental satisfaction with early intervention services. In this study, 32 parents of infant to preschool-age children completed a survey. The parents mostly appeared to be highly satisfied with the programmes that they received, particularly those with more involvement in the programmes; parents who were more involved in their children's early intervention programmes reported higher levels of satisfaction with the services received than did parents who were less involved. A strong association between parental involvement and parental satisfaction is therefore

evident from these results. Additionally, the researchers suggest that parental satisfaction with early intervention programmes was more likely to motivate parents to be involved.

Parents should be seen as equal partners with service providers in decision-making, and professionals are responsible for offering help and support to parents to ensure positive collaboration. Research findings show that a higher level of parental involvement is a significant predictor of parental outcomes such as greater satisfaction with services, reduced family stress levels, enhanced parental well-being, and the development of children's skills.

However, the literature highlights several common barriers to parental involvement in educating children with disabilities in preschool settings. A qualitative study by Wehman and Gilkerson (1999) states that, from the perspective of parents, the most frequent barriers to parental involvement are the inconvenient times at which services are delivered and the lack of communication between parents and practitioners. Lamb-Parker *et al* (2001) investigated possible barriers to participation for mothers whose children had enrolled in the Head Start programme. At the end of the programme year, 68 mothers from low socioeconomic backgrounds were interviewed to fill in a survey on Barriers to Parent Involvement. The results indicated that the mothers experienced difficult situations which hindered their participation; for example, half of the mothers interviewed reported frequent feelings of sadness and depression during part of the Head Start year. Two situations were identified as actual barriers: *"having a schedule that conflicted with Head Start activities"* and *"having a baby or toddler at home"* (p.45).

In order to enhance service outcomes for both children and their families, early intervention programmes should be designed in partnership with parents and professionals to allow parents to take an active role in diagnosing, planning, and implementing early intervention services. Encouraging parental participation can also yield positive results for children with additional challenges, families, and intervention staff. While the findings of the abovementioned studies provide valuable information regarding the positive outcomes of parental involvement and the barriers to their involvement in their children's education, it should be noted that the nature of this involvement is not clear.

3.5 Parenting a disabled child

Research regarding the experience of being a parent of a disabled child is varied, as different disciplines tend to focus on different aspects of this experience. For example, studies in the field of health care are primarily interested in the process of disclosing disability and communicating with health care practitioners, whereas studies in the educational and social fields are more concerned with examining the needs of children with disabilities and their parents. This section is divided into two parts. The first part discusses parental experience of the diagnostic process including disability disclosure, reactions to the identification of disability, and needs as parents of disabled children. The second part examines the impact of disability on families and coping strategies used by parents of disabled children.

3.5.1 Diagnosis of disability

Research studies have taken a wide range of approaches to the process of diagnosing disability. While some of these studies focus on parents' perspectives on the ways in

which their children's disabilities were disclosed and suggest guidelines for effective disclosure, others explored the relationships between parents and health professionals during the diagnostic process, sought to understand parental reactions to the diagnoses of their children's disabilities, or examined the needs of parents of disabled children.

3.5.1.1 Disclosure of disability

Much research has been conducted regarding the moment at which parents are informed of their children's disabilities and how health care professionals communicate with parents during the diagnostic process. Disclosing disability and chronic health conditions is considered one of the most significant challenges that health care professionals encounter (Buckman and Kason, 1992; Dent and Carey, 2006; Graungaard and Skov, 2007). Studies on the disclosure of disability and communication styles between parents and health care professionals show evidence of parental dissatisfaction with current practices. For example, an earlier study conducted by Kerr and McIntosh (1998) utilised focus group techniques to explore parents' perspectives on the disclosure of their children's congenital limb deficiencies. They found that the parents were often poorly informed about their children's disabilities and left the hospital lacking information about their children's cases. Similar findings were reported by parents of hearing-impaired children (Russ *et al.*, 2004), who made negative comments regarding the screening process. Parents also reported long delays in the confirmation of diagnoses and communication difficulties with the professionals who made the diagnoses, which parents felt were not clearly explained.

Another study on this topic was carried out by Baird *et al* (2000), who interviewed parents of children with cerebral palsy using semi-structured interviews and asked parents for their views on the diagnostic process. The interviews yielded mixed responses; although parents generally expressed satisfaction with the disclosure process, they commented on the structure and the manner in which their children's disabilities were disclosed, and on the information given to them.

These results were echoed in Tattersall and Young's (2006) study of parents' experience of diagnostic processes for their hearing-impaired children. Through semi-structured interviews, the researchers revealed that due to dealing with different health care professionals, parents experienced different types of communication during the diagnostic process. The parents interviewed gave examples of both good practice (e.g. professionals showing sensitivity to their situations) and bad practice (e.g. professionals using unclear and complicated language); however, not all parents related these experiences. Parents perceived approachability, patience, and willingness to be accommodating as important characteristics for health care professionals.

Dent and Carey (2006) conducted a review of the literature on delivering diagnoses of disability to parents of children with Down's syndrome. Their review found that most studies over the last four decades took a quantitative approach to this topic, and discovered evidence of parental dissatisfaction with the manner in which health care professionals communicated with them at the time of delivering diagnoses. As a result, Dent and Carey argue that the ways in which healthcare professionals deliver diagnoses to families requires continued improvement.

The time at which parents realise that their children have disabilities may be an unforgettable and stressful moment in their life. Baird *et al* (2000) found that child-parent relationships and parents' ability to adapt to and cope with their children were affected by the manner in which parents were informed about their children's disabilities. Fallowfield and Jenkins' (2004) review of research on the delivery and effect of bad health news supports this argument. The review states that the method in which bad health news is communicated has a lasting impact and that delivering it effectively can aid in acceptance, understanding, and adjustment, while ineffective delivery of such news can lead to anger, stress, and confusion (Fallowfield and Jenkins, 2004). This highlights the need for health care professionals to have appropriate skills and training regarding disclosure of bad news to parents (Dent and Carey, 2006).

The effects of communication between health care practitioners and parents during the diagnostic process have been studied further. Graungaard and Skov (2007) conducted a longitudinal study with parents of eight children aged one to 27 months who had recently been diagnosed with severe physical and intellectual disabilities. The researchers found that the diagnostic process, including the method of communication used and the support provided by health care professionals, influenced parents' reactions to their children's disabilities and the ways in which they coped with their new situations. Parental satisfaction with the diagnostic processes was highly affected by the certainty of diagnoses and the amount of time elapsed before diagnoses were confirmed.

In 17 semi-structured interviews, Fitzpatrick *et al* (2007) asked parents to express their feelings about the process of learning about their children's hearing impairment.

The results indicated that late diagnoses led parents to perceive the diagnostic process as frustrating, confusing, and worrying; parents also reported feelings of regret, anxiety and stress due to their lack of awareness of their children's disabilities.

Previous studies have investigated the factors influencing parents' perceptions of the diagnostic process. The overwhelming nature of the information provided to parents was found to be one of the most influential factors affecting parent satisfaction with the disclosure of disability. For example, Hasnat and Graves' study (2000), wherein 32 parents of disabled children completed a questionnaire on their satisfaction with the diagnostic process, indicates that parents to whom information had been delivered empathetically were more satisfied than those who had not received information (Hasnat and Graves, 2000). Kisler and McConachie (2010) argue that parents require sufficient information about their children's conditions and available intervention during the diagnostic period, and that parents should receive this information as soon as their children's disabilities are diagnosed (Speedwell *et al.*, 2003).

Other factors that may influence parents' satisfaction with the disclosure of disability are the amount of time elapsed between initial suspicion and final diagnosis, the confirmation of diagnosis, the amount of information given, and the way in which that information is delivered (Graungaard and Skov, 2007).

It has been suggested that the task of informing parents about their children's conditions should be carried out by teams of professionals, which might lead to those professionals continuing to provide services to children and parents after diagnosis (Hedderly *et al.*, 2003). Generally, health care professionals play primary roles

during the diagnosis stage, whereas educational, social and other professionals may play major roles at later stages (Rahi *et al.*, 2005). In this respect, many researchers have argued for the creation of guidelines for health care professionals to facilitate communication with families of disabled children at the time of disclosing disability (Baird *et al.*, 2000; Choi *et al.*, 2011; Kisler and McConachie, 2010).

In the aforementioned studies, although some parents expressed satisfaction with the processes of diagnosis and disclosure, other parents recounted examples of health care professionals disclosing the diagnosis of their children's disabilities in a negative manner. Parents of children with disabilities were informed about their children's conditions without being given any positive expectations about their potential; instead, health care professionals tended to focus on their children's deficiencies and provide hopeless prognoses. This may reflect the prevalence of the medical model of disability in the diagnostic process. When health care practitioners adopted an empathetic approach, provided clear and accurate information about children's conditions, and gave parents room for hope, parents often found it easier to adapt to their children's disabilities.

Evidence from non-Western countries is similar to Western countries. Huang *et al.*'s (2010) study highlights the experience of Taiwanese mothers upon receiving diagnoses of cerebral palsy for their children. In this study, researchers interviewed 15 mothers of children with cerebral palsy, as mothers were deemed to be the primary caregivers for their children. Participants expressed mistrust of health care professionals and claimed that they possessed insufficient information about cerebral palsy, were careless and had poor communication skills.

In Korea, Choi *et al* (2011) asked 131 parents of children with Down's syndrome to complete a questionnaire regarding the point at which their children's disabilities were diagnosed. The analysis revealed that parents had received very little information about their children's conditions and the community resources available. Health care providers highlighted the negative points of Down's syndrome rather than discussing any positive aspects of the condition, which made parents pessimistic regarding future expectations, and communication between parents and health care practitioners affected parents' attitudes toward their children at the time of diagnosis.

However, as most of these studies were carried out in Europe or North America, the literature on this topic does not sufficiently cover the process of diagnosing disabled children in developing countries. In particular, there is a dearth of knowledge regarding Jordanian parents' views on how they are informed of their children's disabilities and their experiences of the diagnostic process.

3.5.1.2 Reactions to diagnosis of disability

Previous studies describe common parental reactions to the disclosure of disability as initially negative, such as shock, denial, anger, sorrow, fear, uncertainty and blaming medical professionals. Some researchers characterise these reactions as stages in an adjustment process that ideally culminates in acceptance of and adaptation to disability (Garske and Turpin, 1998; Graungaard and Skov, 2007; Huang *et al.*, 2010). However, negative parental reactions toward disability tend to change as children grow older; as long as their children are developing, parents' negative emotions are likely to decrease in intensity, possibly because they are learning to deal with the difficulties of raising disabled children (Rogers, 2007).

In Rogers' (2007) study, which was based on her reflections on her experiences as a mother of a child with special educational needs, she interviewed 24 parents of disabled children in southern England to explore parents' early emotional reactions upon receiving their children's diagnoses. Participants recalled emotions such as the sense of having lost a normal child, denial, shock, disappointment and acceptance. These reactions were sporadic, did not occur chronologically, happened at various times and in some cases re-occurred. Rogers' (2007) analysis argues that these reactions may facilitate the process of adaptation for parents, stating that "*It is evident that denial can be a positive response, especially in the early days in working through messy and unpredictable periods*" (p.140).

In a study by Russ *et al* (2004), 82 parents of hearing-impaired children in Australia took part in semi-structured interviews regarding their emotional reactions to their children's diagnoses. The reactions reported included negative emotions such as denial, shock, and upset. The intensity of these reactions fluctuated; parents tended to experience less intense emotions when the results of hearing tests were good, and more intense emotions when results were poor.

Heiman's study (2002) examining parental responses to diagnoses of disability revealed that the most common responses to such diagnoses were negative emotions. An analysis of 32 parents' responses highlighted emotions such as depression, anger, shock, denial, fear, self-blame, guilt, grief, confusion, despair, hostility and emotional breakdown. The second most common group of responses included negative physiological reactions such as crying, refraining from eating, and trembling. Parents perceived other family members as reacting positively by providing understanding, support, and encouraging. However, the parents felt that

their initial negative emotions became positive as long as their disabled children were growing up.

Huang *et al* (2010) record similar reactions from Taiwanese mothers, who reported denying the diagnoses they received as they contradicted the traditional perception of having healthy children; some mothers recalled visiting different hospitals to confirm their children's diagnoses. Mothers also reported emotions such as shock, sorrow, and feeling out of control and, due to negative attitudes on the part of health care professionals, hopelessness and powerlessness. Other family members' rejections of their disabled children also increased mothers' feelings of hopelessness.

These studies and the reactions they record are mostly based in developed countries, and in some cases exclude fathers' opinions. It would therefore be inappropriate to apply such results to countries with different health and educational provisions.

3.5.1.3 Needs of parents of disabled children

As the research on parenting disabled children continually highlights the stress, burdens, and disruptions that families encounter, it is reasonable to suggest that parents may require support from different sources. An early study was conducted by Bailey and Simeonsson (1988) to survey the needs of families of children with disabilities. 34 families enrolled in home-based infant intervention programs in North Carolina participated in this study. The results indicated that the need most commonly expressed by parents was a need for information about their children's disabilities, how to teach their disabled children, and what services were available both at the time and in the future.

To understand the role that information plays in the coping process, Pain (1999) interviewed 15 parents of disabled children between the ages of four and eight. Using a coding process, the study identified that parents required information primarily to improve their management of their disabled children, to aid them in the coping process, and to access adequate services and support. Further analysis determined that the possible results of acquiring such information included encouraging parents to be involved in their children's treatment, improving parents' coping strategies, increasing their self-esteem and sense of control, and sharing information about others' experiences, which in turn could reduce feelings of isolation (Pain, 1999). In accordance with this analysis, a study conducted by Taanila *et al* (2002) determined that a group of parents who received accurate and full information about their children's diagnoses and treatment were optimistic about their futures; the information they received helped them to cope with their children more easily and to accept their situations more quickly.

Davies and Hall (2005) argue that seeking information is a positive coping strategy that can ease the adaptation and appraisal process for parents, help parents to maximise their children's potential abilities and regain control over their own lives, and facilitate access to services and benefits. Rahi's studies on the reported experiences of parents whose children were visually impaired confirm these findings (Rahi *et al.*, 2004; Rahi *et al.*, 2005).

Fisher's (2001) examination of eight studies published between 1987 and 1997 on the needs of parents of children with chronic illnesses identifies three primary needs: the need for normality, the need for information, and the need for caring partnerships with health care professionals. This analysis claims that the fulfilment of each of

these needs would work together to facilitate the recovery of control, which was found to be one of the main sources of stress for parents. However, almost none of these needs were met by the health care and social care professionals who provided services to the parents involved.

In a longitudinal study conducted by Speedwell *et al* (2003), parents of visually impaired children acknowledged that the information booklets they received were beneficial, but most parents reported that the time at which they received the information and the amount of information given were unsatisfactory. These results suggest that the written information provided to parents of visually impaired children may not play a significant role in reducing parental stress.

The participants in Hartley *et al*'s (2005) study, who were carers for children with disabilities, stated that they required information, assistive equipment such as hearing aids and wheelchairs, company, and access to special education services to reduce their stress levels.

The literature has identified social, emotional, and intellectual needs of parents of children with disabilities. Meeting these needs would facilitate parental empowerment and allow parents to gain control of their situations, which in turn would help parents to regain a sense of normality and adapt to their children's disabilities. Currently, though, several studies indicate that parental needs are still not being met (Avis and Reardon, 2008; Fisher, 2001; Russell, 2003).

3.5.2 Caring for a disabled child

Parents of children with disabilities normally face many challenges which give them crucial influence over their children's development and life experiences. Previous

studies on caring for disabled children have used a variety of qualitative and quantitative research designs, and some studies have, for comparative purposes, included parents of non-disabled children as well as parents of disabled children. However, the theme of 'stress' emerges frequently, perhaps as a result of the constant burdens placed on the families of disabled children (Voysey, 1975). Parents of children with disabilities often experience higher stress levels than parents of children without disabilities (Oelofsen and Richardson, 2006), which often affects family well-being.

Oelofsen and Richardson (2006) carried out a study comparing the stress and health of families of children with disabilities and families of children without disabilities. Two groups of parents of preschool children completed questionnaires; 59 of the children in question were disabled and 45 were non-disabled. The parents of the children with disabilities reported lower levels of health and higher levels of parenting stress than the parents of the non-disabled children. Additionally, mothers of disabled children expressed higher levels of parenting stress than did their partners. In Mobarak *et al's* (2000) survey of the stress experienced by mothers of young children with cerebral palsy in Bangladesh, 91 mothers of children aged 1.5 to five years were asked to complete questionnaires. Analysis indicated that most mothers experienced stress as a result of caring for their children. Higher stress levels were reported when children had behavioural problems, lacked the ability to perform daily activities, or were older. Mothers who came from rural areas and had low household incomes also reported higher levels of stress. Maternal adaptation was easier amongst mothers who reported lower levels of stress (Mobarak *et al.*, 2000).

The existing literature acknowledges the physical and emotional burdens placed on parents or carers of disabled children. Roberts and Lawton (2001) employed both qualitative and quantitative methods to investigate 40,000 severely disabled children in the UK. The results indicated that the children involved often suffered from physical problems, difficulties chewing and swallowing, behavioural disorders, constant crying, and trouble sleeping for extended periods of time. Analyses of focus group data revealed that they required extra care for activities such as washing, dressing, feeding, using the toilet, and remaining occupied during the night. Meeting these mentioned needs took more time and energy on the part of parents. Roberts and Lawton (2001) stressed that each child and family had unique characteristics, and that professionals should consider this point when assessing the needs of families and their children.

Research has shown that parents of children with disabilities experience stigmatisation, which increases perceived parental burdens. Green (2003) studied the influence of stigma associated with disabled children using qualitative and quantitative methods. 81 mothers of children with disabilities completed a questionnaire, and seven follow-up interviews were conducted. The results indicated that devaluation and stigmatisation of disabled children by others increased maternal distress. Mothers of children who interacted less frequently with their peers perceived a high level of stigma (Green, 2003). In Crawford and Simonoff's (2003) study, parents of emotionally and behaviourally disturbed (EBD) children expressed similar feelings. Interviews were conducted with 30 parents of 25 children enrolled in primary and secondary EBD schools in three south London boroughs. Content analysis revealed that the parents reported negative experiences as a result of being parents of EBD children. These included feeling isolated and stigmatised, being

blamed by professionals and other individuals, feeling unsupported, and experiencing conflicts with services (Crawford and Simonoff 2003). Similar feelings were reported by the six parents of disabled children who took part in Brett's (2004) study. Interpretive phenomenological analysis revealed that some parents experienced feelings of loneliness and isolation and a lack of support. Consequently, these parents felt that they were no longer able to cope with their situations.

Chell's (2006) focus group study on the experience of parents of children with Asperger's syndrome reveals similar results. For the study, 13 parents of children between 3.5 and 16 years of age were recruited and placed in one of two focus groups. Coding processes revealed that some parents felt isolated, stigmatised, guilty, and despairing. These feelings resulted from a lack of awareness about Asperger's syndrome and negative attitudes from some professionals who avoided giving labels to the children in question. While some parents discussed positive aspects of the diagnostic process such as the identification of key workers and gaining access to services, others focused on the painful effects of this process.

Crabtree's (2007) study of mothers of disabled children in the United Arab Emirates (UAE) also reinforces these findings. In the study, 15 Arabic Muslim mothers of disabled children between four and 16 years old were interviewed and asked to share their stories. Some mothers felt repudiated, stigmatised, stressed, and anxious, and experienced feelings of hopelessness and uncertainty for the future. Some found themselves relegated to the status of second wives, and others reported that their husbands had divorced them. Negative attitudes and discrimination from medical authorities and the general public encouraged some mothers to hide their disabled children.

Previous research also points out a range of additional challenges that result from caring for disabled children. In Heiman's (2002) study, most participants felt socially isolated, lacked freedom, and suffered from endless emotional and or physical fatigue. They also experienced financial difficulty with covering special expenses such as private teaching and health care services. Some parents reported that their marriages were negatively affected by having disabled children in their lives, and others highlighted the paucity of accurate information about educational services and social and psychological support.

As a whole, the body of research about families of children with disabilities suggests that parents are exhausted, stressed, stigmatised, isolated, stereotyped, and suffering from poor well-being. These challenges for parents might be generated by complex interactions between internal factors, such as dealing with their children, and external factors such as dealing with individuals outside the family. Such findings indicate that disability is rarely viewed from the perspective of the social model in everyday life.

Social support is a critical factor in helping parents of children with disabilities to adapt to their situations and to maintain and improve their mental health. This is particularly true when families are beginning to learn how to cope with disabled children. In a previous study, parents of hearing-impaired children emphasised the need for emotional support at the time of diagnosis (Russ *et al.*, 2004). In Rogers' (2007) study, parents who received emotional and practical support showed a greater ability to face the difficulties of everyday life, suggesting that parental health and wellbeing can be effectively promoted by formal and informal support. However, parents of profoundly disabled children in Brett's (2004) study expressed different

views on support. Some parents perceived seeking support as an acknowledgment of failure. Others felt that the primary responsibility of caring for their disabled children lay with them and that asking for advice was somehow shameful, while still others stated that their own competencies rendered professional advice unnecessary.

Understanding the stressful situations that parents of children with disabilities face and how parents manage these situations helps service providers to support parents in developing effective coping strategies as well as promoting children's well-being. Taanila *et al* (2002, p.73) define coping strategies as "*the active processes and behaviours that the family actually try to employ to help it to manage, adapt to or deal with a stressful situation*". Familial coping involves striking a balance between family demands and available resources by, for example, looking for pertinent information and acquiring new skills. Coping strategies implement actions and efforts taken by parents of children with disabilities to adapt to their new circumstances and reduce their stress (Sloper, 1999).

In a 2002 study, Taanila *et al* (2002) examined the coping strategies used by families with physically and/or intellectually disabled children. Eight families took part in semi-structured interviews, which were transcribed and analysed using a grounded theory approach. The problems that the families encountered were caused not only by their disabled children, but also by factors such as the relationships between family members. The factors that aided parents' coping processes included information provided by professionals, family cooperation, formal and informal support, and expressing their feelings freely.

Graungaard and Skov (2007) identify the different coping strategies used by the parents in their study as follows: gathering information, obtaining skills, taking into

account the actions and decisions of health professionals, considering new medicines and training, holding on to hope for the future, ignoring the severity of the problem, looking for social support, focusing on their children's abilities, adhering to their beliefs and finding positive aspects to their situations. Crabtree's study argues that obeying religious principles can help by giving meaning or purpose to disabilities (Crabtree, 2007). In this study, the mothers interviewed suggested that their beliefs in God and Islamic morals had led them to accept their children's disabilities.

In Uganda, Hartley *et al* (2005) employed a phenomenological design to understand how carers cope with disabled children. 51 semi-structured interviews were conducted with carers for children with visual, hearing, physical or intellectual disabilities; some of the children in question had multiple disabilities. Four themes emerged from the interviews: the burden of care, poverty, the impact of children's disabilities and communication problems (p.174). Most of the burden of care fell on mothers, with fathers often acting as moderators. A lack of external resources such as financial assistance affected carers' abilities to cope and led them to feel stressed, frustrated, embarrassed and isolated. While carers for children with hearing problems faced difficulties in communicating with their children, carers for severely disabled children struggled to help them with daily activities. The coping strategies most commonly used by participants were seeking cures from medical and traditional sources, seeking support from informal and voluntary organisations, being fatalistic, and accepting their children.

Although the literature predominately investigates the negative effects of having a child with a developmental disability, some studies focus on the possible benefits of parenting a disabled child (Taunt and Hasting, 2002). For example, the participants

in Park and Turnbull's study (2001) appreciated having children with disabilities, as this made them eligible for many benefits such as tax-free services and special parking spaces. Green (2007) argues that as long as a disabled child is growing, the personal benefits for his or her parents increase; for example, parents may eventually become proud of their child's achievements.

Kearney and Griffin (2001) interviewed six parents – two couples and two single mothers – of children with significant developmental disabilities across an 18-month time span. Narrative analysis revealed that the participants experienced two major feelings: joy and sorrow. Parents' relationships with their disabled children were sources of joy, love, and strength, whereas negative attitudes from other people caused sorrow. Although participants generally viewed the experience of parenting disabled children as positive, they reported that negative communication experiences with health care professionals and a lack of understanding from others made them less comfortable with their children's circumstances.

Taunt and Hasting (2002) explored whether families experienced positive outcomes from raising children with disabilities. The researchers collected their data by interviewing 14 white European parents and asking 33 parents from the USA and the UK to complete an electronic questionnaire. Their content analysis revealed that parents reported a range of positive transformations as a result of having children with disability; parents became closer to each other and spent more time together, which strengthened their mutual interactions. These strong relationships helped parents to cope with the consequences of disability, and some parents reported an increase in well-being (Taunt and Hasting, 2002). Consistent with these findings,

61.5% of participants in Heiman's (2002) study indicated that communication with their spouses improved after their children's disabilities were diagnosed.

A study conducted by Green (2007) makes similar arguments regarding the experience of mothering disabled children. The data were collected through interviews with seven mothers and a survey completed by 81 mothers living on the west coast of Florida in the USA. Results revealed that the mothers experienced feelings of joy and love through appreciating their children's achievements, learnt not to evaluate people based on appearance, and increased their abilities to deal with different situations and a range of service providers. The presence of disability in the participants' lives also deepened their relationships with their families or friends.

A more recent study in Sweden conducted by Boström *et al* (2010) aimed to explore parental attitudes towards children with intellectual disabilities. 17 parents of intellectually disabled children between five months and five years of age took part in semi-structured interviews. Interpretative phenomenological analysis revealed that most parents expressed joyful and positive emotions when describing their children, and that some parents' stories indicated quick acceptance of their disabled children. However, some parents struggled to understand their children and faced communication difficulties as a result. Additionally, most parents in the study reported feeling uncertain and frustrated when their children's disabilities were diagnosed.

The studies reviewed suggest that children with disabilities typically have higher care needs than children without disabilities and that this is associated with increased levels of parental stress. Stress levels fluctuate over the years and tend to be more prevalent at the time of diagnosis. Parents can generally cope well with their disabled

children if they have developed functioning coping strategies and are offered appropriate support. However, some of these studies do not openly discuss the process of interviewing and analysis, and do not clearly state which methods of analysis were used to interpret data. There is also an absence of research on the coping strategies used by Jordanian parents of disabled children or their unique needs.

3.6 Parents' perceptions of services

Unlike parents of non-disabled children, parents of disabled children are often involved with many types of services, such as health care services and special education services. In recent years, there has been an increase in research seeking to understand parental perceptions of the services delivered to them and their disabled children. Information on parents' views of these services assists in the development of programmes (Rodger *et al.*, 2008), which in turn leads to encouraging parents to take part in educating their disabled children. When the views and opinions of service users are investigated, service providers and professionals have the opportunity to re-think the ways that they can support disabled children and their families (Sloper, 1999). Parents' points of view on the services tell professionals how services should be delivered and what parents want from these services (King *et al.*, 2001). Brett (2004) states that *"viewing parents as experts and giving them a voice in research legitimises their perspective and is an important step in using their experience to consider alternative ways of offering support"* (p.18).

Paradice and Adewusi's study (2002) investigates parental views of educational provisions for children with Speech, Language, and Communication Difficulties (SLCD) in England. 51 parents of children from two to 17 years of age with SLCD

were placed into focus groups and asked to express their views on the services provided to their children. With regard to primary provision, one group of parents was happy with the services provided, while other groups highlighted weaknesses such as children's needs being unmet and the limited availability of specialists. In terms of secondary provision, parents felt that their children were left without support in inclusive provision⁶, and that enrolling their children in adequate schools was a struggle; some parents also faced problems with travelling to their children's schools. All parents claimed that teachers did not supply sufficient information about their children's progress, and wanted more information on how their children's needs were being met by their schools.

The parents involved in Crawford and Simonoff's (2003) study had mixed experiences with service providers. While some parents appreciated their communication with professionals, others expressed dissatisfaction with professionals who failed to deliver sufficient information and devalued them by referring them to other services and by seeking to deny their own responsibility. Some parents also reported feeling denigrated by professionals. Staff members were not appropriately trained or experienced, and frequent staff changes were problematic as well. Participants expressed positive attitudes towards EBD schools and voluntary organisations, but reported poor experiences with social, health, and childcare services. Additionally, many parents highlighted their needs for support and wanted to share their problems with other parents.

Avis and Reardon's (2008) study explores English parents' perceptions of the services they and their disabled children received while their children were in

⁶ The term inclusive provision is used in this thesis to mean integrated services catering for both disabled and non-disabled children.

hospital. In this study, semi-structured interviews were conducted with 12 parents of children with disabilities. The most significant theme that emerged from these interviews was that of communication, with parents stating that nurses should be good communicators. Parents felt that nurses were unable to communicate effectively with them and with their disabled children, and argued that nurses were unable to meet their needs for information and emotional support.

Checker *et al* (2009) developed a questionnaire to investigate parental perspectives on the services received from visiting teachers. 34 parents of hearing-impaired children living in regional and rural Western Australia completed the questionnaire. Researchers concluded that parents were generally satisfied with these services but wanted more concentration on specific skills and extra sessions.

Parental satisfaction is a pervasive theme in the literature and may be used as a measure of quality of the services provided to children with special needs. According to Rodger *et al* (2008 p.174), “*Satisfaction refers to the degree to which parents feel that a service meets their needs and those of their child*”. Parental satisfaction with services can aid in determining the essential factors, strengths and weaknesses of the services in question, and represents evidence of the programmes’ value (Summers *et al.*, 2005a). This latter function can persuade decision-makers to be supportive by, for example, funding programmes for children with disabilities. While a growing body of research uses quantitative instruments or established questionnaires to survey parental satisfaction, only a few studies use qualitative methods to examine this same issue.

King *et al* (2001) recruited two groups of parents of children with special needs, asking them to describe ‘what they liked best and least about the services provided

for their child' (p.115). Based on the literature, the researchers devised a coding scheme with an overarching framework shaped by three elements: structure, process, and outcome. The findings suggested that parents tended to be more satisfied when service providers were respectful and supportive to them and their children. More comments were made on 'process' than on 'structure', suggesting that the ways in which services were delivered were more important than what was delivered. Dissatisfied parents made more comments on 'structure' than satisfied parents. According to these results, both 'process' and 'structure' are required for parental satisfaction with services.

A study by Summers *et al* (2005b) appraises the satisfaction of parents of disabled children with special education services in the USA. 147 parents of disabled children aged 12 and under were asked to complete the Beach Centre Family-Professional Partnership Scale. Findings revealed that while parents expressed a relatively high level of satisfaction with the services they received, their satisfaction decreased as their children grew older. For example, parents of children aged six to 12 were less satisfied than parents of children aged three to five.

Whitaker's (2007) study examines the satisfaction, experiences, and perceptions of parents whose children received special education provisions in Northamptonshire in England. A postal questionnaire was completed by 173 parents and carers of children with Autism Spectrum Disorder (ASD). While 61% of respondents rated themselves as satisfied or very satisfied with the special education services provided for their children, 39% of respondents rated themselves as dissatisfied. The parents and the carers were more satisfied with special schools or unit-based provision than with mainstream provision. Parents of children who had special education statements were

more satisfied than parents of children without such statements. Both the satisfied and dissatisfied groups regarded understanding their children's needs and developing social skills as the highest priorities for them and their children.

Rodger *et al's* (2008) exploratory case study investigates the factors that influence parental satisfaction with early intervention programmes. The researchers recruited two mothers who had children with ASD and were identified as reporting low levels of satisfaction. Several questionnaires and semi-structured interviews were administered. The most significant factors emerging from these related to children, parents, and the delivery of services. The main factor influencing parental satisfaction with early intervention programmes appeared to be the improvement of children's development, whereas parenting stress levels were the main factor affecting parents. Topics discussed regarding the delivery of services included parents' relationships with facilitators and the level of competence the facilitators demonstrated by being able to provide individualised information, communicating effectively, and understanding children's and parents' needs.

Parsons *et al's* (2009) recent study investigates the satisfaction of parents and carers of special-needs children with educational provision in England, Wales and Scotland. Data were collected from a survey completed by 562 parents. Respondents reported that they generally experienced positive support from their children's schools, were positively supported by disability legislation, and were able to choose affordable schools for their children; they also noted that no constraints stopped their children from accessing optional activities in their schools. Parents of special-needs children in mainstream educational settings were less satisfied than parents of special-needs children in special schools.

Park and Turnbull's (2001) study explores Korean parents' perspectives on the special education services they received. Eight parents of children with special needs were interviewed via telephone. Analysis of the data revealed that Korean parents were satisfied and impressed with the special education system in the USA as they received a good quality of services and valued the help that they received from mediators. However, some parents experienced frustration when communicating with professionals due to language barriers, and five of the eight parents interviewed believed that their children would receive greater attention in a non-inclusive setting.

In Crabtree's (2007) study, immigrant mothers in the UAE were satisfied with the services provided. However, citizen mothers were dissatisfied with these services, reporting that the services failed to modify their children's behaviours or develop their everyday skills, such as toilet training and speaking, which might enable them to integrate into mainstream society. Some participants also mentioned a lack of specialists in special education centres.

Although parents in previous studies appeared to be highly satisfied with the services they received, this does not mean that they were satisfied with all aspects of these services. King *et al* (2001) suggest that satisfaction and dissatisfaction are not mutually exclusive; dissatisfied parents in their study were able to see positive aspects of the services they received. Therefore, satisfaction is multidimensional and can be affected by different variables.

The sample sizes in most studies were also small and were only concerned with one unit or type of service, which makes generalisation difficult. Additionally, although there are a small number of qualitative studies involving parents of disabled children, the majority of research in this area employs quantitative research methods.

Therefore, there is still a need for further qualitative research involving parents whose children receive special education services to understand how these services could be more effective.

3.7 Conclusion

Although this literature review presents results from different nations and cultures, there are some points that should be considered. First, most of the research studies covered were conducted in western countries. Second, the majority of participants in these studies were mothers; it is important to consider this when attempting to apply these findings to parents' experiences in general. Third, the research on the experiences of parents of visually impaired children is limited when compared to research on parents whose children have other types of disabilities. Fourth, some of these studies are concerned with parents' experiences of specific programmes or specific services. Fifth, parents' perspectives on special education services are predominantly investigated through quantitative rather than qualitative methods. Finally, there is a limited amount of research investigating parental experience of parenting disabled children in the Arab world; more specifically, there appear to be no studies concerning parental experiences of caring for disabled children and receiving services and support in Jordan.

This study seeks to remedy these gaps in knowledge by exploring the experience of parenting disabled children in Jordan and investigating the services provided for children with disabilities and their parents, starting from the time at which parents first suspect that their children may be disabled. The present study also extends previous research attempting to understand the nature of caring for a child with a disability and engaging with professionals who provide services to disabled children.

Understanding parents' experiences of having children with disabilities and receiving disability-related services may help policy-makers and service providers to overcome the difficulties that parents face and eventually improve disabled children's abilities to reach their full potential. This study hopes to effect such positive change for Jordanian children with disabilities and their families.

Chapter 4: Research methodology

4.1 Introduction

This chapter describes and discusses the methodological approach employed in the study by outlining the following: the design of the study; discussion of the researcher's epistemological position; consideration of the ethical issues involved; methods of sampling and recruiting participants; data collection methods; data analysis methods; limitations of the study; and procedures used to establish rigour and maintain credibility during the research process.

4.2 Design of study

This study utilises a qualitative interview design, which is a common approach within social research (Bryman, 2008; Murphy *et al.*, 1998). With regard to early intervention services, this was endorsed by Sandall et al (2002) as a valuable way of recording participants' voices so that others may appreciate their situation: *"Qualitative research has the potential to increase our understandings of children with special needs, their families and those who work for and with them. Certainly, qualitative research has the potential for deepening our understanding of the intervention issues and challenges that children with disabilities and other special needs pose (2002, p.130)"*.

With respect to this study, the choice of a qualitative design was governed by the study's aims and research questions, which focus on how parents of disabled children make sense of their lives and experience diverse events, and understanding the experience of parenting a child with a disability in various situations and settings in Jordan (Willig, 2008). The exploratory and interpretive nature of a qualitative study

allows greater flexibility for parents to talk in depth about their feelings and opinions on the issues being investigated (Dawson, 2007).

This study does not seek to test theories that were specified in advance of data collection (Bryman, 2008), gather or analyse numerical data or discover cause–effect relationships (Willig, 2008); therefore, a quantitative design would not be useful. Rather, the research was designed to explore attitudes, behaviour and experiences, as expressed in the respondents' own words and answers to 'how' and 'what' questions during interviews (Dawson, 2007). A qualitative interview study of this kind is free standing, but may also facilitate other future qualitative or quantitative investigations (Bryman, 2008; Murphy *et al.*, 1998), either through replicating the same set of questions with different research samples or constructing a structured survey based on the source study's qualitative findings. Thus, Murphy *et al.* state that: "*A qualitative study may help to define the dimensions that a quantitative study would aim to measure and to suggest effective ways of asking questions by describing the language used by or intelligible to the population being examined* (1998, p.3)". Additionally, the rich descriptive information gained from a qualitative study design (Murphy *et al.*, 1998) itself may carry sufficient weight to persuade policy makers to improve the quality of services for disabled children and their parents.

4.3 Epistemological position

Epistemology is the study of the nature of knowledge and the methods utilised to obtain it. "*It attempts to provide answers to the question, 'How, and what, can we know?' This involves thinking about the nature of knowledge itself* (Willig, 2008, p.3). Explaining my epistemological position can further explain the approach and methods chosen for this study. In line with my desire to undertake an applied study

that might 'make a difference' to the situation of disabled Jordanian children and their parents, I have adopted a realist position (Murphy *et al.*, 1998). According to the realist paradigm, reality exists independently of the researcher and has certain enduring features that continue to be important irrespective of the methods utilised by the researcher to understand the subject of interest.

Within the qualitative research tradition many studies build in realist assumptions by appealing to such notions as the value of first hand observation of social settings or of face-to-face interviews that elicit the accounts of subjects in their own terms. In doing this they stress the value of 'naturalism' (fidelity to the phenomenon at hand) (Matza, 1969), 'being there' (Roth, 1966), or 'telling it as it is' (e.g. Melia, 1982). Yet there has always been another strand of qualitative scholarship that has stressed the pitfalls of thinking that direct contact with subjects gives easy access to their inner thoughts, and argued that there are multiple realities, actively created by participants themselves rather than existing in a fixed external world. These radical versions of constructivism raise valid questions about the complexity of subjective experience and representation, but open the way for a form of relativism in which the findings of one research project have no more value than the accounts put forward in other studies, or for that matter the various everyday accounts offered when ordinary people talk about the topic of interest.

Hammersley (1992) explains that many qualitative researchers find themselves making an uncomfortable choice between a 'naive' realism that underplays the complexity of subjective perspectives, and a relativism that denies the possibility of cumulative gains in knowledge and is doubtful about the practical value of findings. Hammersley's (1992) 'subtle realism' is an attempt to assert the reality of the

external world and its problems, while not falling into the trap of believing that research simply records how things are in a non-problematic way or glossing over problems of interpretation and selective perception. His solution is a more careful specification of what realism involves. Hammersley's position can be summarised as follows:

- Reality exists independently of the researcher's knowledge claims.
- However, knowledge of phenomena is always gained from a particular social location and theoretical standpoint.
- Research accounts represent reality rather than reproducing it.
- Any reality can be represented from a range of different perspectives, but just as some claims are true others may be false.
- There is the possibility of multiple valid, non-competing representations of social phenomenon where versions of reality directly contradict each other they cannot all be valid (see: Hammersley, 1992, pp. 50 - 52).

Within Hammersley's framework, empirical investigation and careful attention to methodology are important because research can provide data on realities that are beyond the researcher's control, and proper understanding of how things can inform policies that make a real difference for real people. The framework has attracted support from a number of qualitative researchers interested in applied research that aims to help formulate pragmatic social policy solutions (Murphy *et al.*, 1998; Mays and Pope, 2000), and it is the one adopted in this study. My aim was to represent the reality of the experiences of parents of disabled children from the parents' perspectives (Murphy *et al.*, 1998).

My realist position does not imply that my account is an entirely objective one. Like any researcher I come to this study with certain pre-existing values and perhaps even biases. As Creswell (2007, p.20) states, “...researchers recognize that their own background shapes their interpretation, and they ‘position themselves’ in the research to acknowledge how their interpretation flows from their own personal, culture, and historical experience”. This certainly applies in my case. My belief in the importance of the services provided for young children with disabilities and their parents, particularly in the early stages of disability, has been shaped by my personal experiences, beliefs, and values. Having worked for over ten years in special education, I recognise and appreciate the complexities of parenting disabled children and the support required for parents to manage their situations. My professional experience includes teaching children with intellectual disabilities, deafness, and specific learning difficulties; working as a training field supervisor for university students studying special education; collaborating with principals and teachers in special education schools in Jordan and teachers to set up and monitor teaching practice for trainee school employees; and a lecturer post at Al-balqa Applied University, where I taught course modules and worked as a co-researcher in the Department of Special Education. These experiences have shaped my interest in parental perspectives on Jordanian special education services for young disabled children, particularly since little attention is given to this topic in Jordan. Further, being Jordanian means that I am able to speak the participants’ language fluently and understand their culture and behaviours. All these factors influenced the way I approached the study, including my choice of topic, choice of study design, data collection methods, and interpretations of the data collected.

4.4 Ethical considerations

Prior to the commencement of this study, ethical approval was sought from two institutions. First, I formally applied for, and was granted, approval to carry out this study from the Ministry of Education (MoE) in Jordan. The procedure and requirements for obtaining such approval can be summarised as follows:

- 1- A general formal application for research access (there was no separate requirement for ethical approval) was submitted to the Minister of Education's office, together with an attached outline of the research aims, data collection methods, and expected interview questions. Two formal letters were also attached to the application: one from my supervisor at Swansea University and the second from my sponsor in Jordan.
- 2- The application was passed to the Department of Educational Research in the MoE, and subsequently referred to the Directorate of Special Education.
- 3- After approximately two weeks, formal letters were prepared for me to send to different Local Educational Directors (LED) in Jordan. These letters requested permission for me to conduct my research and asked for assistance to facilitate research access.
- 4- I took these formal letters to the LEDs, and each LED prepared formal letters to send to the various schools and kindergartens that were candidates for inclusion in the study.
- 5- I contacted the principal of each school and kindergarten in order to arrange a meeting with him/her. In these meetings, I again outlined the purposes of my research and what it would entail, and explained how the institution would need to co-operate in contacting parents and obtaining their consent.

6- For those special education institutions not supervised directly by the MoE (i.e. operating in the private sector), I contacted their principals directly to explain the research aims and procedure, and the assistance required from them to facilitate my study.

Secondly, ethical approval was obtained from the research ethics committee at Swansea University. This depended on meeting requirements such as obtaining signed consent from participants, preserving participants' anonymity, providing participants with the opportunity to withdraw from the study at any time, maintaining data confidentiality and keeping interview transcripts secure.

4.5 Sample

In qualitative social research, the sampling methods chosen depend on the purpose of the study. In purposive sampling, participants are selected based on the assumption that they can provide data relevant to the phenomenon of interest (Creswell, 2007) and are thus 'relevant to the research questions' (Bryman, 2008, p.458). In this study, the sample was relatively small and was purposefully selected from a specific target population – parents of young children with disabilities in Jordan – with a view to investigating the research questions that had been set (Bryman, 2008). Parents were selected to include an appropriate demographic spread, in terms of educational level, monthly income, parents age and gender, and family size so that the study could examine a range of perspectives and experiences (Creswell, 2007).

The following two sections describe the research participants in more detail, explain the criteria for sample selection and the process of recruiting participants, and highlight the difficulties encountered during the recruitment procedure.

4.5.1 Participants

Participants in this study were Jordanian parents whose children had been identified as disabled, were between four and six years of age, and were receiving early intervention and/or related services from public- or private-sector institutions. The criterion of having children between four and six years old was based on the assumption that the experience of early intervention services would be fresh in parents' minds, in contrast to parents with older children who would not have dealt with such services for some years and might not be able to accurately recollect their experiences. Additionally, it would have been difficult to identify a sample of parents with younger children, as no official record of statistic and demographic data for disabled Jordanian children in this age group was available, and the schools/kindergarten would not be able to help with recruitment of subject.

64 parents – 25 fathers and 39 mothers – of special-needs children took part in 53 interviews. These parents had pre-school-age children who were blind, deaf and/or intellectually disabled. Within the group of children who had intellectual disability, there were five children who had additional disability, namely physical disability. The number of parents who participated in the interviews is shown in the table (4).

| | Father | Mother | Total |
|---------------------|---------------|---------------|--------------|
| Blindness | 6 | 15 | 21 |
| Deafness | 13 | 7 | 20 |
| Intellectual | 6 | 17 | 23 |
| Total | 25 | 39 | 64 |

Table 4: Number of parents interviewed for each disability category

The parents were between 28 and 47 years old, and their educational levels ranged from very low (illiteracy) to PhD-level. Their household incomes were also diverse, ranging from JD 200 to 1500 monthly. Family sizes were similarly varied; parents in this study had between one and 10 children. At the time of the interviews, all the disabled children were between 4 and 6.4 years old and were living with their biological parents. In 42 out of the 53 families interviewed, the disabled child was the last born in his/her family. Table (5) provides details for each participant.

It is important to note that in the Jordanian system, children with different disabilities that affect the brain – such as Down’s syndrome, Fragile X syndrome, autism and cerebral palsy – are often treated in the same facilities. These children were considered to fall into the ‘intellectual disability’ category for this study.

A decision was taken not to include parents of children with physical disabilities only because there were no special kindergartens for these children. Younger physically disabled children are often treated in normal kindergartens since they do not have sensory or cognitive difficulties, and may thus be deemed to be more acceptable in an inclusive setting. There were no published data indicating the numbers of physically disabled children and where they might be found. Thus contacting parents of this group would have been difficult.

| No. | Family | | | | | Disabled child | | | | |
|-----|----------------|--------|-----------------------------------|-----------------|-------------|-------------------|-----|--------|--------------------|-----------------------------------|
| | Interviewee | Age | Educational level | No. Of disabled | Family size | Monthly income JD | Age | Gender | Type of disability | Ordinal position |
| 1- | Father | 45 | High school | 1 | 7 | 400 | 6 | M | Hearing | 4 th |
| 2- | Father | 47 | High school | 1 | 5 | 500 | 5 | M | Down's syndrome | 5 th |
| 3- | Mother | 41 | Diploma | 1 | 8 | 280 | 6 | M | Intellectual | 8 th |
| 4- | Mother | 42 | Primary school | 1 | 4 | 300 | 5 | M | Intellectual | 4 th |
| 5- | Mother | 45 | High school | 1 | 4 | 350 | 4 | F | Down's syndrome | 4 th |
| 6- | Mother | 45 | Secondary school | 1 | 6 | 280 | 6.5 | M | Cerebral palsy | 6 th |
| 7- | Mother& Father | 41/ 42 | Higher school (both) | 1 | 5 | 200 | 6.4 | M | Hearing | 5 th |
| 8- | Mother& Father | 38/ 44 | Diploma/ Primary school | 1 | 6 | 300 | 6.5 | M | Hearing | 4 th |
| 9- | Mother | 37 | High school | 1 | 4 | 500 | 5 | M | Down's syndrome | 4 th |
| 10- | Mother | 43 | Secondary school | 1 | 7 | 400 | 5 | F | Intellectual | 7 th |
| 11- | Mother& Father | 42/41 | Bachelor's degree (both) | 1 | 3 | 1000 | 4.2 | F | Intellectual | 2 nd |
| 12- | Mother | 30 | High school | 1 | 3 | 300 | 5 | F | Fragile X | 3 rd |
| 13- | Mother | 33 | Bachelor's degree | 1 | 5 | 700 | 6 | F | Intellectual | 2 nd |
| 14- | Father | 48 | Primary school | 1 | 10 | 300 | 6.3 | M | Hearing | 8 th |
| 15- | Mother | 41 | High school | 1 | 5 | 400 | 5 | F | Hearing | 5 th |
| 16- | Father | 44 | Higher school | 1 | 6 | 600 | 6 | M | Hearing | 6 th |
| 17- | Mother | 43 | Diploma | 1 | 4 | 400 | 6.5 | M | Autism | 4 th |
| 18- | Mother& Father | 45/47 | Higher school (both) | 1 | 5 | 500 | 6.4 | M | Vision | 5 th |
| 19- | Mother | 30 | Diploma | 1 | 3 | 500 | 5 | F | Vision | 3 rd |
| 20- | Mother& Father | 30/41 | Secondary school/ Diploma | 1 | 3 | 500 | 5.5 | F | Vision | 3 rd |
| 21- | Mother& Father | 38/43 | Secondary school/ High school | 1 | 5 | 250 | 5 | M | Vision | 5 th |
| 22- | Mother& Father | 42/48 | Bachelor's degree/Master's degree | Twin | 3 | 2000 | 4 | F/ F | Vision | 2 nd / 3 rd |
| 23- | Mother | 48 | Illiterate | 1 | 7 | 250 | 5.5 | F | Vision | 7 th |
| 24- | Mother | 41 | Diploma | 2 | 4 | 1000 | 6/5 | F/ M | Vision | 3 rd / 2 nd |
| 25- | Mother | 43 | Secondary school | 1 | 2 | 300 | 6 | M | Vision | 2 nd |
| 26- | Mother | 42 | Secondary school | 1 | 1 | 200 | 6 | F | Vision | 1 st |
| 27- | Mother | 38 | High school | 1 | 5 | 230 | 6 | M | Vision | 4 th |
| 28- | Mother | 42 | Diploma | 1 | 5 | 600 | 5 | M | Vision | 5 th |
| 29- | Father | 39 | Diploma | 1 | 6 | 650 | 5.5 | M | Hearing | 1 st |
| 30- | Father | 48 | Diploma | 1 | 5 | 400 | 5 | M | Hearing | 5 th |
| 31- | Father | 28 | High school | 1 | 4 | 200 | 5.3 | M | Hearing | 1 st |
| 32- | Mother | 42 | Diploma | 1 | 7 | 300 | 6 | M | Hearing | 7 th |
| 33- | Father | 46 | PhD | 1 | 6 | 1000 | 5.6 | M | Intellectual | 6 th |
| 34- | Father | 42 | Diploma | 2 | 7 | 450 | 4/6 | F/ F | Hearing | 6 th / 7 th |

| | | | | | | | | | | |
|-----|-----------------|-------|----------------------------|---|---|------|-----|---|-----------------|-----------------|
| 35- | Mother | 34 | High school | 1 | 4 | 500 | 5.8 | F | Cerebral palsy | 2 nd |
| 36- | Mother | 40 | Diploma | 1 | 2 | 700 | 5.2 | F | Down's syndrome | 2 nd |
| 37- | Mother & Father | 43/45 | Bachelor's degree (both) | 1 | 2 | 1500 | 4.8 | M | Intellectual | 2 nd |
| 38- | Mother | 36 | High school | 1 | 2 | 1000 | 4.2 | M | Autism | 2 nd |
| 39- | Mother | 34 | Bachelor's degree | 1 | 2 | 800 | 6 | M | Autism | 2 nd |
| 40- | Mother & Father | 32/34 | Secondary school/Diploma | 1 | 2 | 400 | 5 | M | Vision | 2 nd |
| 41- | Mother | 32 | Bachelor's degree | 1 | 1 | 1000 | 4.6 | M | Vision | 1 st |
| 42- | Mother | 28 | Diploma | 1 | 2 | 350 | 5 | M | Vision | 1 st |
| 43- | Mother | 40 | Diploma | 1 | 2 | 400 | 5.1 | F | Vision | 2 nd |
| 44- | Mother & Father | 36/38 | Bachelor's degree (both) | 1 | 3 | 600 | 4.9 | F | Intellectual | 3 rd |
| 45- | Father | 40 | High School | 1 | 4 | 450 | 5.1 | F | Down's syndrome | 4 th |
| 46- | Mother | 37 | Diploma | 1 | 4 | 340 | 5.5 | M | Intellectual | 4 th |
| 47- | Mother & Father | 36/36 | Diploma/ Bachelor's degree | 1 | 5 | 450 | 4.6 | F | Hearing | 5 th |
| 48- | Mother | 38 | Diploma | 1 | 5 | 300 | 4.9 | F | Hearing | 5 th |
| 49- | Mother | 33 | Bachelor's degree | 1 | 3 | 300 | 5.1 | F | Hearing | 3 rd |
| 50- | Father | 42 | High school | 1 | 2 | 260 | 5 | F | Vision | 2 nd |
| 51- | Father | 35 | Bachelor's degree | 1 | 3 | 600 | 4.8 | M | Hearing | 3 rd |
| 52- | Father | 29 | Diploma | 1 | 1 | 400 | 5 | M | Hearing | 1 st |
| 53- | Father | 41 | High school | 1 | 4 | 350 | 4.7 | F | Hearing | 4 th |

Table 5: Detailed information about the parents and their disabled children

Keys:

M: refers to male

F: refers to female

Diploma: refers to a degree certificate awarded when a candidate successfully passes two year course after completing high school.

4.5.2 Recruitment process

Twelve institutions that served young children with disabilities were approached to identify respondents for interviews. Through these schools and kindergartens 107 invitation letters were sent to the parents along with recruitment materials, which included a participant information sheet (appendix I) and consent form (appendix II), asking them if they would like to take part in this research. 21 of the parents approached replied refusing to take part, 59 replied agreeing to participate, and 27 did not return the forms. Those parents who agreed to participate received a further letter indicating that the researcher would contact them in order to arrange a convenient time and date for an interview. Of those parents who initially agreed to participate, 4 parents did not arrive for interview and 2 parents made their apologies and cancelled their interview (Figure 2). Perhaps parents who refused to participate or who did not send the invitation back had no time to take part in this research, or it may be that some were affected by the sensitivities surrounding disability. For example, some parents may feel shame when others know that they have a disabled child in their families and this makes them choose non-participation.

The specific criteria for participation in this research were as follows: (a) the selected parent had a child with a disability, (b) the child had received early intervention services in Jordan within the four months prior to data collection, (c) the parent was the primary caregiver for the child, and (d) the parent indicated willingness to participate.

From my past experiences in this field, I was aware that Jordanian parents of disabled children might not readily come forward to participate in this study. It would have been culturally unacceptable to offer financial incentives to participants,

meaning that there was no real way to encourage participation. As a result, recruiting participants for this study proved challenging.

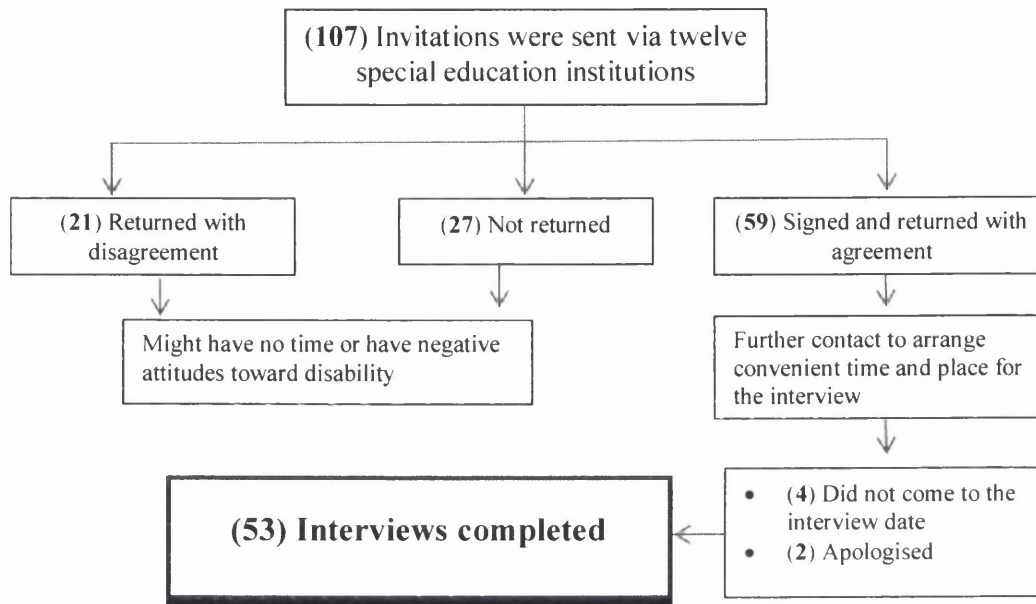


Figure (2): Parents who were approached.

The initial problem was obtaining local permission from the MoE. Seemingly, there was no systematic procedure for conferring such permission. The official with whom I met in the MoE was not familiar with qualitative methods; he consistently asked me to provide a copy of my questionnaire so that my application could be considered, stating that “*All students who ask for a facilitation letter to conduct a research study should provide a copy of their questionnaire*”. I had to arrive at a pragmatic compromise of treating the interview as though it were on a fixed schedule, providing a list of questions, and explaining how the interview would be administered. This was judged acceptable by the official.

The second barrier was the attitudes that some principals of special education institutions held toward contacting parents. They regarded parents of children with

disabilities as similar to bereaved parents and suggested that engaging them in interviews would remind them of their situation. One principal stated: *“Parents are fed up and some of them don’t want anyone to know that they have a disabled child. However, I promise we will send your sheets to them, but I think they won’t accept. I would suggest that you construct a questionnaire, which would be an easier way to obtain information”*. Again, most of the principals that I approached suggested that distributing a questionnaire was the preferred method for collecting data from parents of disabled children, and that asking to meet parents face to face was unusual. I had to repeatedly explain the advantages of qualitative research to the principals in order to gain their assistance with contacting parents. However, three principals expressed enthusiasm for the study and invited me to attend their upcoming monthly parents’ meetings, where I could meet parents directly. I attended these meetings, introduced myself and described the aims of the planned study and what the interviews would entail. I also answered questions from some parents regarding my research. This personal contact worked well in these settings with more parents agreeing to take part in the study. The responses to my access requests were useful research data in their own right and I recorded the gist of my interactions with principals and others in research fieldnotes.

The third challenge encountered was convincing the parents who were contacted to be interviewed, since they were unused to participating in this kind of research and having their voices recorded. Some said that filling in a survey would have been much easier for them. To reassure the parents involved, I provided them with more a detailed explanation of the aims of this research and how the study might benefit them as a group. I was also careful to emphasise that the information they provided would be dealt with anonymously and in confidence.

Locating a suitable time and place was also difficult, since the choice of interview location and time was left up to participants. When parents preferred to be interviewed in their children's kindergartens, for instance, I was responsible for making the necessary arrangements with each kindergarten. In some cases, I had to call parents several times before an interview could be arranged.

In addition, I had to cope with cultural norms that restricted my interactions with female interviewees, particularly when the family in question came from a very conservative community. As a male researcher, it would have been culturally unacceptable for me to interview a mother (or any woman) alone. This proved difficult when some mothers expressed a willingness to participate but their husbands were unable to attend. To overcome this obstacle, mothers were allowed to be accompanied by an adult family member during the interview, and/or interviews were conducted in a public place such as the kindergartens that the participants' disabled children attended. Both approaches proved effective; 17 mothers chose to be interviewed in kindergartens, while 11 mothers chose to be accompanied by a family member.

These challenges gave me a better understanding of the value and uniqueness of my research, and (to my mind) confirmed the necessity of collecting face-to-face interview data to remedy the information gap in this area.

4.6 Data collection

Data collection was completed in two sets of open-ended qualitative interviews. 35 parents – 12 parents of intellectually disabled children, 8 parents of deaf children and 15 parents of blind children – took part in the first series of interviews. The second

series of interviews involved 29 parents: 11 parents of intellectually disabled children, 12 parents of deaf children and 6 parents of blind children (table 6). Because fieldwork involved trips to Jordan which were expensive and might lead to complications with immigration clearance, I had decided I needed to do fieldwork in substantial blocks. However, I also realised that as a neophyte researcher I would benefit from feedback from my supervisor in the light of how my early interviews had gone. Because of the difficult practicalities of the situation, I decided to do about half my interviews and then review progress with my supervisor before completing the second series of interviews on a second trip.

After the first round of interviews, I reviewed the transcripts of a small number of (translated) example interviews with my supervisor and some deficiencies were identified. For example, it became evident from examination of some interviews that I had not explored certain questions in sufficient depth, moving to the next question too quickly when the respondent might have said more. My supervisor suggested that I should be prepared to let silences stretch a little longer or use non-directive probes to encourage the respondent to continue. There were also some issues where respondents touched upon topics not included in my original interview guide questions that seemed highly relevant, and I therefore decided to add additional questions covering these areas in the second round (see Appendix IV, p.273). This does not mean that I only talked about these topics in the second series of interviews, as they had been raised by some informants on their own initiative, but now I made a point of questioning all future respondents on these matters.

This section highlights the strengths of the semi-structured interview method by justifying the selection of semi-structured practice and describes how these interviews were conducted.

| Type of disability | 1 st series = 28 interviews | | | + | 2 nd series = 25 interviews | | | Overall |
|--------------------|--|---------|--------|---|--|---------|--------|---------|
| | Intellectual | Hearing | Vision | | Intellectual | Hearing | Vision | |
| No. interviews | 11 | 6 | 11 | | 9 | 11 | 5 | 53 |
| No. interviewees | 12 | 8 | 15 | | 11 | 12 | 6 | 64 |

Table 6: Number of interviews and interviewees in each series

4.6.1 Semi-structured interviews

The semi-structured interview was selected as the main means of data collection. This interview technique was deemed the most suitable for exploring the perspectives and opinions of parents who deal with the complex and sensitive issues involved in caring for disabled children. Seidman (2006, p.14) notes that such interviews are “...a powerful way to gain insight into educational and other important social issues through understanding the experience of the individuals whose lives reflect those issues”.

Dawson (2007) states that semi-structured interviewing is perhaps the most common interview technique used in qualitative social research, perhaps because the transcribed data can be analysed in many different ways (Willig, 2008). This is probably because semi-structured interviews’ are flexible enough to explore unanticipated areas, can elicit views as expressed in the respondents’ own words, and generate a degree of empathy which cannot be achieved in a survey.

In semi-structured interviewing, *'the interviewer might re-word, re-order or clarify the questions to further investigate topics introduced by the respondent'* (Tong *et al.*, 2007, p.351). Doing this allowed me to follow up any interesting questions that arose during the interview so that other important information could emerge (Bryman, 2008; Dawson, 2007; Murphy *et al.*, 1998), and to compare and contrast the information gained with the results of other interviews (Dawson, 2007).

In these interviews, I focused on a number of interrelated areas, including the process of diagnosing children's disabilities, parental perspectives on communication with health care professionals and other service providers, the impact of disability on the family, access to local services, other people's understandings of disabilities, coping strategies, and perspectives on different aspects of services and support. However, as the interview was designed to be flexible, parents were given the opportunity to discuss other issues as well. In other words, this technique of interviewing allowed me to look at various aspects of parents' experience which I would not previously have considered to be pertinent (Murphy *et al.*, 1998).

Some consideration was given to supplementing the interviews with focus groups, but this was eventually ruled out. In the Jordanian cultural context, some people would likely express support for others' ideas whether or not they agreed with these ideas; therefore, focus groups would not allow for the free sharing of information and opinions. In particular, some women might not feel comfortable sharing their views in a mixed-sex focus group. Some parents would probably be wary of speaking openly within the group for political reasons, especially on topics related to government services. Arranging a suitable time and place for a group of parents to be interviewed together at the same time would also have been difficult. Furthermore,

since the aim of this study was to understand the experiences of individual parents, it was not considered suitable for this study.

In total, 53 semi-structured interviews were carried out with 64 parents of young children with disabilities (table 7). Of these 53 interviews, 20 were conducted with parents of children diagnosed with intellectual disabilities, 17 were conducted with parents of children diagnosed with hearing disabilities, and 16 were conducted with parents of children diagnosed with vision-related disabilities. In 11 of these interviews, parents were interviewed together as couples. This was considered acceptable when the parent initially approached opted to involve the spouse in the study, but was not actively encouraged. 28 interviews were with individual mothers, and 14 interviews were with individual fathers (table 8). Of these 64 parents, 23 were parents of intellectually disabled children, 20 were parents of deaf children, and 21 were parents of blind children. Full details on each interview and participant can be found in table (5).

| Type of disability | No. interviews | No. interviewees |
|--------------------|----------------|------------------|
| Intellectual | 20 | 23 |
| Hearing | 17 | 20 |
| Vision | 16 | 21 |
| Total | 53 | 64 |

Table 7: Number of interviews and interviewees in each disability group

| | Couple (father and mother) | Father only | Mother only | Total |
|--------------|----------------------------|-------------|-------------|-------|
| Intellectual | 3 | 3 | 14 | 20 |
| Hearing | 3 | 10 | 4 | 17 |
| Vision | 5 | 1 | 10 | 16 |
| Total | 11 | 14 | 28 | 53 |

Table 8: Breakdown of interviews in each group of children with disabilities

4.6.2 The interview process

After the potential participants had agreed to take part in this study and provided me with signed consent forms, I telephoned parents who met the selection criteria to arrange a convenient time and location for interview and to answer any questions they had. On meeting the parents, I endeavoured to establish rapport and maintain it during the interview (Willig, 2008); this enabled me to break down any social barriers between myself and the parents and to create an atmosphere of trust, so that parents would be encouraged to speak freely and openly. This was achieved by introducing myself and disclosing details about myself, such as my academic and work background and personal life (being married and having two daughters). Before the interview began, I reiterated the parents' right to refuse to answer any given questions or even to withdraw from the interview, and emphasised that all data would be kept confidential. I also made it clear to the parents that they would not be identified at any stage of the research process.

At the commencement of each interview, parents were asked to fill in a brief questionnaire with demographic details about themselves and their disabled children (appendix III). The demographic data collection was followed by a series of open-ended questions. All interviews were conducted in Arabic, as it was the native and preferred language of the participants.

All interviews were recorded using a small digital recording device which I borrowed from my university department. To ensure good recording quality prior to each interview, I used a checklist suggested by Dawson (2007, p.68):

- Ensure that enough space is available on the recorder to record the interview.
- Check the capability of the recorder batteries.
- Have a spare memory source.
- Ensure that there are no sources of audio interference in the room.
- Place the recorder on a suitable surface.
- Check that the microphone can properly catch the voices.
- Ensure that the recorded data file can be transferred to computer.

Table 9: Recording checklist adopted from Dawson (2007, p.68)

To maintain a comfortable atmosphere for participants during each interview, I followed strategies suggested by Dawson (2007) and Seidman (2006), such as speaking less and listening more, tracking parents' responses, offering clarifications and/or re-phrasing questions when participants expressed confusion; composing extra questions to gain a clearer response; and as far as possible conveying appropriate body language. Each parent interviewed related their experiences as a chronological narrative beginning from the time of discovery of their child's disability.

While the interviews were being conducted, many parents chose to call me 'akh Mizyed'; 'akh' means 'brother' in Arabic. In Jordanian culture, referring to someone by this term indicates that the speaker feels reasonably comfortable and safe with the other person, and is a sign of trust and acceptance.

During and after each interview, I made field notes to record body language and other contextual information that would not have been effectively captured on the digital audio recorder. For instance, some parents enthusiastically showed examples of their disabled children's work. I also recorded impressions of the interviews in my notes (Bryman, 2008). After interview number 37, for example, I wrote that "...the

interview was held in a very nice room and went very well; the parents were eager to talk; and some refreshment was provided". [field note]

Additionally, I wrote self-evaluation notes about my interactions with parents during the interviews. This process helped me to remain aware of my role as a researcher and to avoid making judgments regarding parents' ideas. I also reflected on how I could best manage participants' anxieties, fears and concerns to set parents at ease and encourage them to disclose more information.

To ensure that the interviews covered all necessary topics (Bryman, 2008, Dawson, 2007), an interview guide was prepared (appendix IV) which allowed me to 'tick off' topics as they were covered. However, the order and style of the questions on the guide were not fixed; sometimes questions from the guide were left unasked or other questions were added to better obtain relevant information from the interviewees. The questions on the interview guide were developed based on pre-existing literature and suggestions from my supervisors. The interview guide covered a variety of areas relating to the experience and perspectives of parents of children with disabilities, including: interaction with healthcare practitioners and service providers; accessing services; special-education institutions; involvement in their disabled children's education; the impact of these interactions on their families and disabled children; and available support. Additionally, the parents were asked to provide suggestions to improve the services for disabled children in Jordan. This range of topics offered flexibility for the parents to discuss and raise issues that they considered important (Dawson, 2007).

The interviews ranged between 45 and 90 minutes in duration, lasting until participants had nothing more to say and all necessary topics of enquiry were

covered. 29 interviews were completed in the participants' homes, 20 in their children's kindergartens, and four in the participants' workplaces (in their private offices).

4.7 Data analysis

Data analysis was carried out thematically according to the procedure suggested by Braun and Clarke (2006). Thematic analysis, which can be defined as 'a method for identifying, analysing and reporting patterns (themes) within data' (Braun and Clarke, 2006, p.79), was used to examine interview transcripts and written comments, guided by the reviewed literature and my understanding of what constituted the key issues of this study. This section justifies the choice and describes the process of thematic analysis.

Given the number of interviews conducted, I considered using an automated approach, via a programme such as NVivo, to analyse the data. Unfortunately, such programmes were not compatible with languages written from right to left such as Arabic, in which my interviews were conducted and transcribed. It was not feasible to translate the complete data set into English. First, translating hundreds of pages would require a great deal of time and money. Second and more importantly, it was believed that culturally specific terms or concepts might be altered or lost in translation.

Although thematic analysis is widely used in qualitative research, it is rarely acknowledged as a sufficient technique in itself (Braun and Clarke, 2006). Instead, it is deemed to be the core ingredient of many other approaches to qualitative analysis, such as grounded theory, narrative analysis, and content analysis, which are used to

identify patterns and themes in qualitative data sets (Braun and Clarke, 2006). Further, Braun and Clarke argue that *“thematic analysis should be seen as a foundational method for qualitative analysis. It is the first qualitative method of analysis that researchers should learn, as it provides core skills that will be useful for conducting many other forms of qualitative analysis”* (2006, p.78).

Thematic analysis can be applied across a range of theoretical and epistemological approaches, including essentialist paradigms, and research questions (Braun and Clarke, 2006). Thus, thematic analysis appeared compatible with this study’s realist paradigm. Thematic analysis is also more open and exploratory than other methods of analysing qualitative data, which allows it to provide a rich, detailed, and complex account of data and – in this case – to identify commonalities and differences between participants. Additionally, the transparency of the thematic analysis method will enable future researchers to evaluate this study and use it in their own research.

Grounded theory and similar methods were deemed unsuitable for this study. As grounded theory is concerned with theory development and requires detailed theoretical and knowledge and complex coding processes. As this study was not concerned with developing theories and my experience with qualitative research is limited, I decided to employ the more accessible thematic analysis method to analyse my data.

According to Braun and Clarke (2006), there are a number of decisions that must be made prior to commencing analysis:

- How should themes be identified? A theme is an implicit topic that organises a group of repeating ideas (Auerbach and Silverstein, 2003; Creswell, 2007).

Thus, a theme should relate to something that addresses research questions and aims rather than the most prevalent elements across a data set. For this study, a thematic unit was considered to be a concept that would advance understanding of the situation of the parents of disabled children; together, these units represented how the participants experienced being parents of disabled children in Jordan.

- Should one favour a balanced description of the whole data set, or a detailed account of one particular aspect of the data? As my participants' views on the topic were not known (Braun and Clarke, 2006), I aimed for a rich thematic description of the entire data set to provide a sense of the predominant and important themes for readers.
- Inductive versus theoretical thematic analysis: I identified the pattern within the data using an inductive method; coding the data did not involve trying to fit it into a pre-existing coding frame or analytic preconceptions.
- Semantic or latent themes: I aimed to identify themes at a latent level, examining the content of, and seeking meaning in, the data.
- Epistemology, or essentialist/realist versus constructionist thematic analysis: as mentioned earlier, I adopted a realist perspective.

Braun and Clarke (2006) break down the thematic analysis approach into six phases (table 10).

| Phase | Brief description of the process |
|------------------------------------|--|
| 1. Becoming familiar with the data | I transcribed the interviews and my field notes, followed by reading and re-reading all data many times while initial ideas were written down. |
| 2. Generating initial codes | I coded the interesting features (patterns) of the data systematically across the entire data set. Data relevant to each code were collated. |

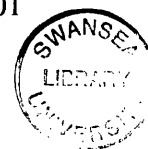
| | |
|-------------------------------|---|
| 3. Searching for themes | I collated codes into potential themes and gathered all data relevant to each potential theme. |
| 4. Reviewing themes | I checked whether themes worked in relation to the coded extracts (Level 1) and the entire data set (Level 2). |
| 5. Defining and naming themes | The analysis continued until the specifics of each theme were refined and the overall story of the analysis was told. Clear definitions and a name for each theme were produced. |
| 6. Writing up findings | This phase was the final opportunity for analysis. Example extracts were selected, and the analysis was linked to the research questions and literature. Four chapters were produced to tell the overall story of the data. |

Table 10: Phases of thematic analysis adapted from Braun and Clarke (2006, p. 87)

Before describing how the analysis was carried out within the six phases of thematic analysis, it should be mentioned that this was a recursive process, wherein I moved between phases in a non-linear fashion as needed (Braun and Clarke, 2006). However, the six phases are detailed in order below for clarity.

Phase one: Becoming familiar with the data

This phase involved transcribing all conversations with participants and linking the field notes with their relevant interviews. The 53 transcribed interviews, complemented by their field notes, were closely read many times and the main ideas from the data were underlined. All of the interviews were transcribed and analysed in Arabic, my native language, in order to make it easier for me to examine the converted text, capture the meanings of the narratives, and ensure that subtleties were not lost in translation. I conducted and transcribed all the interviews myself, which increased my closeness to the data, my motivation to identify key themes, my consciousness of similarities and differences between parents' reports (Bryman, 2008), and my detailed understanding of the data.



Phase two: Generating initial codes

After multiple readings of the transcripts were carried out, relevant passages of transcribed text were coded. Coding involves organising the text of a transcript in order to detect patterns within its structure (Auerbach and Silverstein, 2003) and in the meanings attached to a phenomenon by the research participants (appendix VI). Seidman describes coding as '*The process of noting what is interesting, labelling it, and putting it into appropriate files*' (2006, p.125). For this study, coding involved breaking down the data into discrete segments, identifying and categorising units of meaning, tagging these categories with an appropriate term, and collating similar categories into themes. As I went through the whole text, I extracted relevant texts on separate sheets and titled these textual segments with meaningful labels. Labels that came up on multiple occasions were given a code, and a long list of codes was built, which were then used to think about more general study themes.

Phase three: Searching for themes

In qualitative analysis, identifying themes is the primary task carried out by qualitative researchers, regardless of the approach they use (Ryan and Bernard, 2003). Accordingly, I began determining how codes could work together to form themes. As the potential themes seemed large and complex, they were broken down into sub-themes to ensure a hierarchy of meaning within the data. Sub-themes emerged by sorting the codes identified in the previous phase in groups of codes based on shared attributes. The codes were laid out on separate sheets; each individual code was combined with relative codes; and each group of codes was also combined with a relative group to form a sub-theme. Afterwards, sub-themes were collated based on their interplay to analyse broader meanings and major themes.

Each sub-theme was given an appropriate name, and each theme was titled with keywords. I used tabling to aid in sorting the different codes into potential sub-themes and themes.

Phase four: Reviewing themes

In this phase, I reviewed the potential sub-themes and themes as well as the identified codes by re-reading all data and re-checking relevant texts. Some codes were more likely to be merged with other codes to avoid redundancy (Braun and Clarke, 2006). For example, two themes were combined with each other to form an overarching theme. I went through the entire data set and all codes many times until I felt that no further amendment was needed. The aim of this refinement and reviewing process was to ensure that codes were entirely connected to the data and that themes fitted together coherently.

Phase five: Defining and naming themes

Final reviewing of the data was carried out in this phase. A few of the codes were classified more clearly for consistency, and codes and themes were re-labelled when necessary. Some themes were renamed to more clearly reflect what they dealt with (Braun and Clarke, 2006). Themes were further refined to ensure that each theme told a clear story. Figure (3) shows the final themes and sub-themes and details how these mesh together to provide an account of the experiences of parents of pre-school children with disabilities in Jordan.

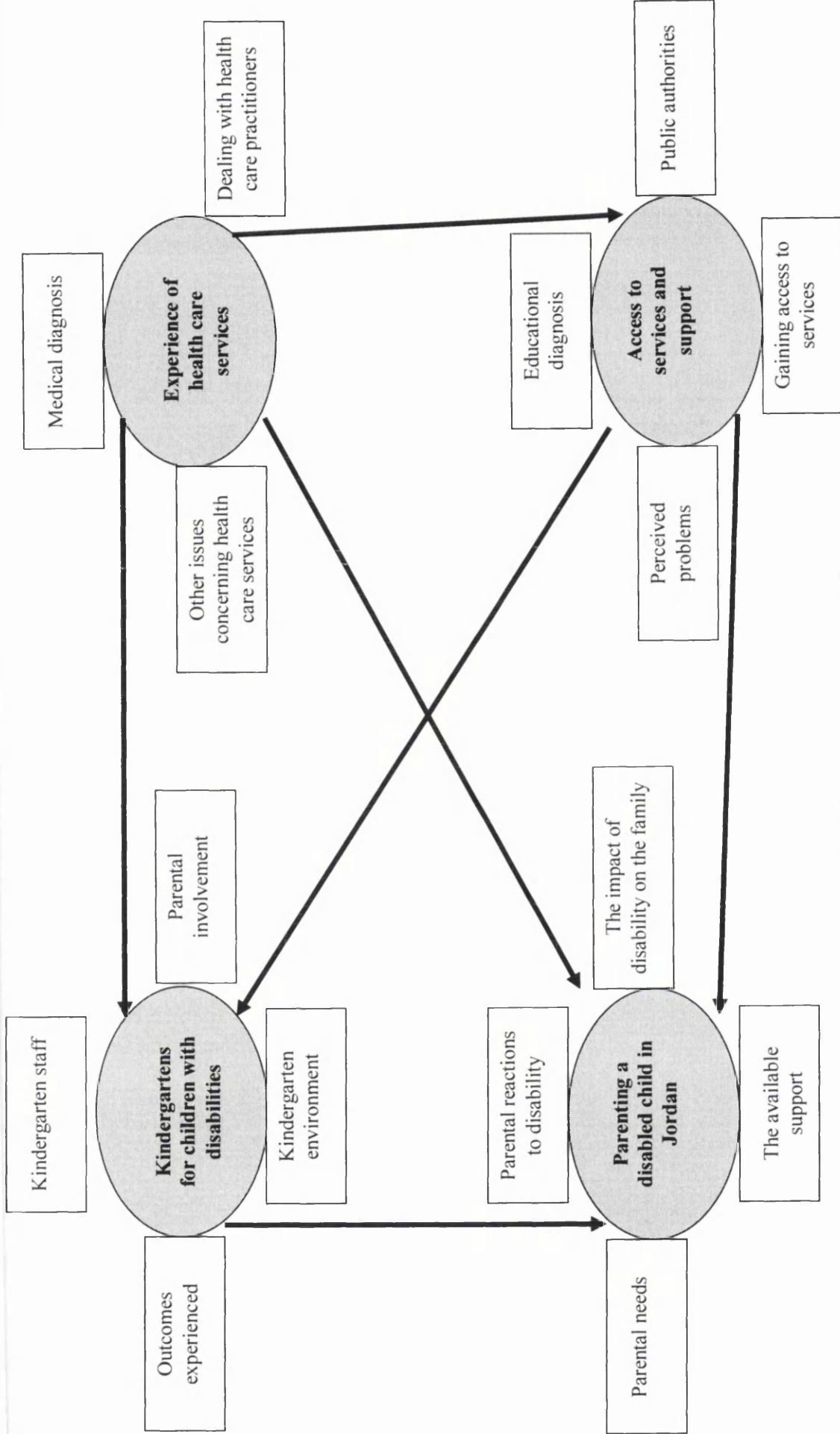


Figure (3): Major themes and related sub-themes.

Phase six: Producing the report

After the analysis was completed, the results were presented according to the emergent themes in a report. All themes, subthemes, codes, and selected quotes were translated into English. Four chapters of the report (chapters 5-8) provided a detailed explanation of participants' experiences and the overall story emerging from the data. This framework of themes, sub-themes and coding categorises was illustrated with vivid examples from the data extracts (Braun and Clarke, 2006). All quotations were kept anonymous to protect the identities of parents and their children and pseudonyms were used throughout. These chapters were organised to provide a chronological narrative of the experiences of parents of young disabled children with regard to health care provision, access to special education services and support, and kindergartens, how it looks like to be a parent of disabled child in Jordan. The account finished by outlining parents' suggestions for how these services could be improved, in light of their experiences to date.

4.8 Limitations

As with most research studies, there are some limitations to this study that must be acknowledged.

- As mentioned previously, the sample size used in this study was relatively small. This is a common limitation of qualitative studies, and can be addressed by completing further studies that test the findings of the initial research.

- Parts of my interviews concerned disabilities which were diagnosed several years ago. The time elapsed between the interviews and these diagnoses might have affected the accuracy of parents' accounts of their early experiences of care, and especially how the diagnosis was communicated.
- The results of this study cannot be considered generally applicable to all Jordanian parents of young children with disabilities because of possible sample selection effects. All parents in this study participated voluntarily, and may have different characteristics from parents of disabled children who were not willing to share their experiences (Auerbach and Silverstein, 2003).
- Since I was a lone researcher and responsible for all data collection and analysis, the research process may have been influenced by my own personal experiences, intentions, and values, as mentioned earlier in this chapter.

4.9 Validity

Creswell and Miller (2000) report that a variety of terms are used to refer to the validity of research, such as authenticity, goodness, trustworthiness, adequacy, and validity. To establish validity, I used several techniques. One of the strategies used to strengthen qualitative research is describing findings thoroughly and in depth (Creswell and Miller, 2000), which is accomplished in the following four chapters of this thesis.

Member checking (Bryman, 2008; Creswell and Miller, 2000), which could alternatively be called respondent validation or informant feedback, was also used to establish validity. This involved asking all participants if they would like to comment on, and give their impressions and confirmation of, their interviews (Bryman, 2008).

Fifteen full transcripts were sent back to those parents who wished to do this in order to check the accuracy of their interviews. These parents were then asked to add to, delete from or amend their interview transcripts as needed. All expressed their satisfaction with the records of their interviews and did not make any corrections or amendments.

Another technique used to enhance the validity of this research was reflexivity. I have openly discussed the processes of interviewing and analysis, clarified my role as a researcher and detailed my awareness of my participants' cultural background. Disclosing my 'identity, credentials, occupation, gender, experience and training' (Tong *et al.*, 2007, p.351) also contributed to reflexivity.

Ongoing supervision added validity to this study as well. Throughout my research process, I was advised by my supervisor. The study was carried out via two rounds of interviews with a break in between, which allowed the results of the first round to be reviewed and deficiencies to be remedied before the second round of interviews took place. After the first round of interviews, a group of interview transcripts was translated into English. My supervisor checked these transcripts, asked for more data to be collected and posed extra questions suggesting that some lines of inquiry needed to be explored in greater depth. After analysing the initial round of interviews, it became apparent that some codes needed to be saturated and that some significant points required additional investigation. These concerns were taken into account in the second round of interviews. After the final analysis was concluded, categories and emergent themes were discussed with my supervisor and altered based on this discussion.

4.10 Introduction to the results

In my presentation of the key findings, the themes are to be viewed as a whole, and to be understood within the context of the experiences of parents of disabled children. Most of the categories are not independent from each other. Under each category, an appropriate quotation from a participant is provided to achieve one or more of the following aims: supporting the category; explaining and illustrating the issue being discussed; increasing comprehension; and providing a space for the participant's voice to be heard.

The following four chapters examine the major themes emerging from the collected data. These findings are clustered under four main headings: parents' experience of health care services (chapter 5); access to services and support (chapter 6); kindergartens for children with disabilities (chapter 7); and parenting a disabled child (chapter 8).

4.11 Summary and conclusions

This chapter has discussed the design of the study and the methods used to answer the research questions. It detailed the rationale for the selection of qualitative methodology, particularly the semi-structured interview technique, and discussed the researcher's epistemological position. The procedures for selecting, recruiting and gaining access to participants and gaining access were described, as was the process of generating data via interviews. This chapter then justified the choice of thematic analysis to analyse the data and detailed its six phases. Finally, while this study

acknowledged its limitations, the chapter listed the different strategies used to establish validity and ensure that the analysis met required quality standards.

Chapter 5: Parents' experience of health care services

5:1 Introduction

Health care encompasses a wide range of services, but in this study it refers to the services that children with disabilities received while they were meeting specialist physicians, general practitioners (GPs), and other professionals during the periods when they were in hospital. In the research interviews parents of children with disabilities told their stories about health care services, going back to the time they first suspected a problem in their child's development.

This chapter examines different aspects of health services experienced by parents. These are entitled 'parents' experience of health care services' which forms one of the major themes analysed in this study. Within this theme, three subthemes were identified: dealing with health care practitioners; medical diagnosis, and other issues of health care services. Also, each subtheme covers different dimensions of parents' experience of health care services. Figure (4) shows the categories used to understand the experiences of health care services.

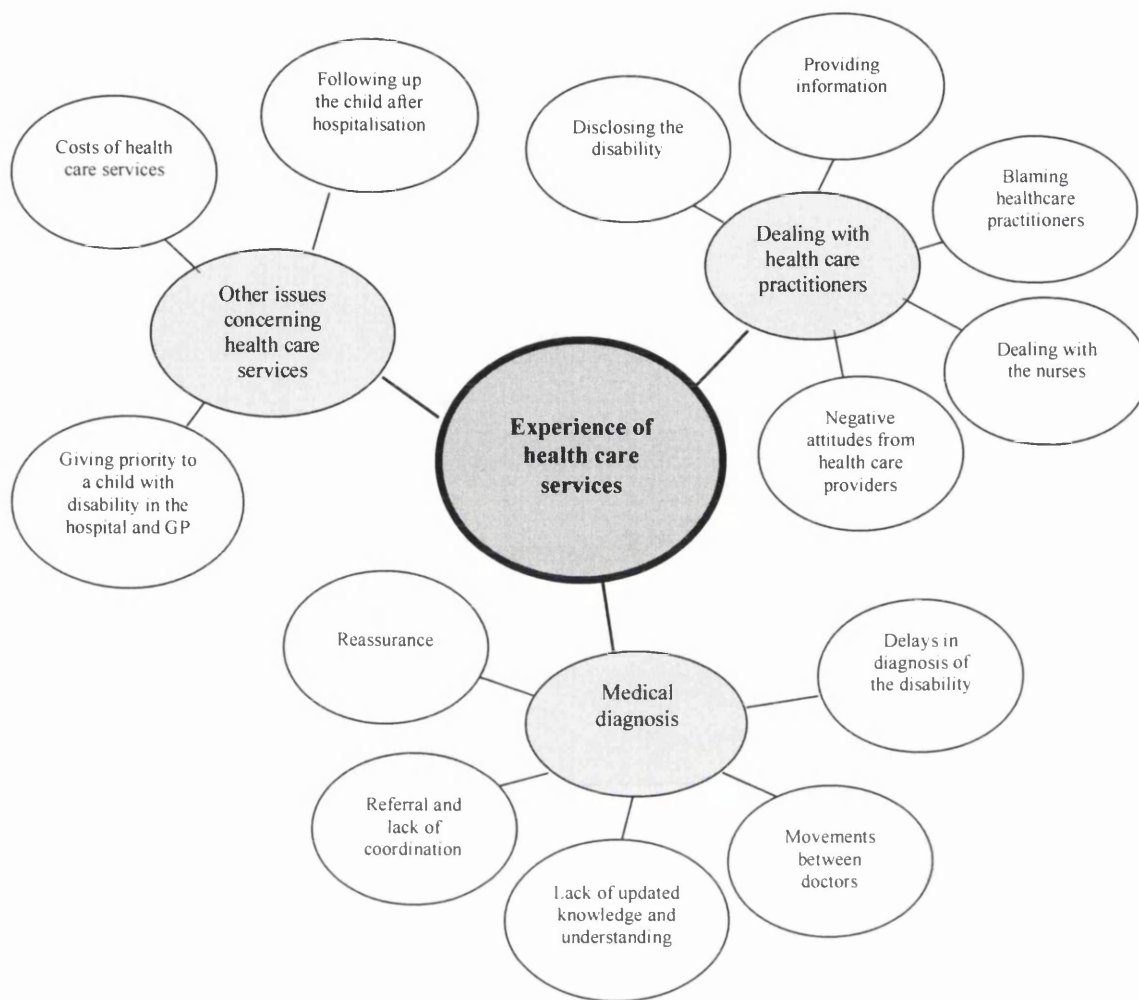


Figure (4): The main categories of response for the first emergent theme, 'parent's experience of health care services' including the three subthemes and related categories.

5:2 Dealing with health care practitioners

Generally speaking, when parents suspect their child has a developmental problem, they will seek professional help to try to identify the nature of the problem and a solution, and will almost always do that by approaching health care staff rather than some other category of professional expert. Some parents may already be in contact

with health care practitioners, usually in cases where their child's problem was suspected just before or after the birth. This section discusses parental experience of dealing with health care practitioners; even they contacted the services early or later. In this context, five issues were highlighted by the parents.

5:2:1 Disclosing the disability

Chronologically, the discovery of the disability was the first experience highlighted by parents, particularly for parents of children with congenital disability. Few had been able to themselves make a diagnosis of the problem, and first learned that their child was disabled when this information was disclosed by a health care professional. When parents described the situation of being told that their child was disabled, most of them, particularly the mothers, were unhappy with the way in which the professional had dealt with them. The bad news was primarily delivered by physicians and other health care professionals: for parents of intellectually disabled children, the news was usually delivered by a paediatrician; for parents of blind children, this was the responsibility of an oculist, and in most cases of deaf children, parents were told by an audiologist. However, parents often felt that professionals could have used a different approach in informing them about their child's problem. The majority of respondents believed that this news was delivered badly. From their interview accounts, many doctors viewed disabled children in terms of the symptoms of the specific disability involved, concentrating on the child's lack of abilities. They tended to describe the condition and the cure available, rather than talk about the individual child before them. This was coupled with a lack of detailed information about the child's case, which might have helped parents to understand and to become

more familiar with their new situation. For example, Faten is the mother of a child with Down's syndrome. Describing how she was informed of her child's disability, she said:

I still remember, the doctor was unkind. (My husband was not there), the doctor came and told me directly "Your daughter has Down's syndrome". I recognised what this meant, as I had written an article about Down's syndrome before. I asked him, "Are you sure?!" he answered "Yes, trust Allah (God), and live with her as she is!" I didn't feel the doctor was talking kindly or sympathetically. I'll never forget that.

Mother of a child with an intellectual disability

This view contrasted with that of some parents interviewed, who were satisfied with the way the bad news was delivered. When health care professionals engaged with parents in discussion about the child's case, and emphasised the child's abilities rather than lack of ability, the disclosure of the condition was perceived as satisfactory. When probed in the interviews such parents suggested the disclosure process, that the health professional had made extra efforts in their case. In several cases parents mentioned that they themselves were working in the medical care field, or had a good rapport with the physicians who delivered the news.

When I was lying on the bed at the hospital, the doctor came and told me, "There are many children born with Down's syndrome, these children have reached an advanced level in their lives, they can be educated and work. I'm suspecting that your child is going to be Down's syndrome, you need to look after him carefully". He gave me a contact number of a specialist in special education... that doctor was great, we have been in contact with him since 2000".

Mother of a child with an intellectual disability

Although most parents did not receive information or sympathy from health care professionals, some of them did not report any problem with the direct way the bad

news was delivered; they perceived it as normal. To some extent this way of disclosing the disability was acceptable by those parents because they tended to give justifications without commenting on the communication style between them and health care practitioners. This may suggest that those parents adopted the idea that doctors are for diagnosis and offering treatment, not for anything else.

To be honest, he told me about my child's case in a normal way. Basically he told me "your son is suffering from hearing loss". You know, the doctor is checking up too many cases in his work and there is a queue waiting for him, so he supposes your child's case is like thousands of other deaf children, he doesn't have enough time to look for the best way to break the news, he is practical.

Father of a deaf child

5:2:2 Providing information

Even where a diagnosis was made it did not always answer all the parents' questions and might not be entirely conclusive. Thus many parents experienced a period of uncertainty that spanned their initial contacts with health professionals and in some cases continued for several years. During this period parents were seeking information about the condition, and its management and the implications for the family. They also needed information about the services available. This was particularly true during the first stage of awareness of the disability. The parents expected most of the information they needed to come from the doctors, whom they looked to for an explanation of the child's situation and the causes of the disability, knowledge which might have helped them to reconstruct their new life. However, most doctors focused mainly on treatment of the child rather than advising the parents; they did not direct the parents to educational or social support or guide them regarding how to access special education services.

The doctor diagnosed my daughter as suffering from lack of oxygen. At that time, I didn't know what lack of oxygen meant. Ok, I asked the doctor, "What do you mean by lack of oxygen?" He didn't answer me. You know, the hospital was filled with patients and the doctor had no free time to talk to me. He only told me, "Your daughter has lack of oxygen".

Mother of a child with an intellectual disability

It can be assumed that within the system of Jordanian health services, there is a weakness in the provision of providing information about the long term effects of disabilities, and the community support that might be available for parents. In hospitals and GP practices, most parents of children with disabilities were seeking information about the services that were available in the local community, and how they could access these services. But this information was not given to the parents.

We asked the oculist, but he didn't know anything. We thought that he was the right person who would tell us about the people who could help us and provide services for our daughter, but no one helped us.

Mother of a blind child

While some parents perceived this information deficit as a sign of the limitations of the doctors, other parents believed that it was not the doctors' responsibility to provide information.

They (the doctors) knew the child's problem and didn't know anything else. They didn't have any idea about directing you. This was a big issue. They didn't tell me what the next step should be. I don't think they knew if there were any special education centres or kindergartens for such children. When I left the hospital, I didn't know where to go.

Mother of a child with an intellectual disability

In some cases, both parents and health care professionals saw disability as a personal tragedy - a personal trouble rather than a public issue (Mills, 1959). Those parents who adopted this view were often more likely to perceive that the disability was their

problem and that they had to deal with it, and they did not expect information to come from doctors.

He (the doctor) never told me where I could find services for my child. I think the doctor's work stops where he can define the disability. He can diagnose the problem but his work stops there.

Father of a deaf child

The need to provide information and its influence on parents is highlighted by the fact that those parents who expressed their satisfaction with the way they had been informed about their child's disability, were the ones who had been given information about their child's case and some links to available services. In other words, parents who felt they received information about their child, and the special education services they could access, were more likely to be happy with how their child's disability was disclosed. The information that had been given to these parents might help them in reducing future ambiguity and in coming to terms with their child's disability.

5:2:3 Blaming practitioners as part of the reason for the child's disability

Some parents claimed that the lack of specialised skills on the part of health care staff in terms of dealing with their child's situation was a reason for their child's problem. The competencies of health care practitioners were criticized at all stages, including labour, care after the birth, diagnosis and treatment. Some parents believed that the reason for their children's disabilities was neglect by the hospital staff. A parent, for example, stated that the nurses dropped her daughter, which in her view caused her disability.

On the first day, my daughter was normal, her head circumference, size, and weight were ok. I've had two kids before and I know how a normal baby looks. So, next day when they brought my daughter at 5:30 am, there was a piece of bandage filled with blood under her head. I called the nurses and asked them, "What is this?" They replied: "It's nothing to worry about, it's normal, it's a minor injury" They took my daughter away. My daughter disappeared for five hours. I called my doctor and asked him about the baby, he told me, "Don't worry it's a simple wound and it will heal within a few days". With a new-born baby, it's impossible that is a minor or surface injury. Two weeks after I left the hospital I took my daughter to another doctor...he told me, "There is a broken bone in her head; probably she was dropped while she was in hospital. Take care of her".

Mother of a child with an intellectual disability

Some parents of blind children claimed that their children were not given enough care or attention from health care professionals, particularly just after birth. Sammer is the father of a blind child, who consistently claimed that his child did not have appropriate amount of oxygen while he was in the incubator.

They checked my son three times and operated on his eyes. They found that his retina was melted. This was because he had been given a high dose of oxygen. The doctor told me there is no treatment for him. I took my son to another oculist and tested him again. The oculist confirmed that the high dose of oxygen caused the disability.

Father of a blind child

Some of the parents who felt that the inadequate and possibly damaging health care provided to their children in hospital had caused the disability or exacerbated the problem, had attempted to sue the hospital. But the parents could not prove their claim as it was hard to obtain conclusive evidence. Some accounts may indicate to using atrocity stories by the parents; the idea is that parents constructed themselves as unselfish people and presenting their efforts to care for their disabled child in a positive light whereas the professionals were insensitive and uncaring (Voysey, 1975).

5:2:4 Dealing with the nurses in hospital

Some parents, particularly those who recognised their child's disability just after birth, spoke about their communication with the nurses. Often the conversations were about parents attempts to reconstruct what had happened. However, the nurses did not understand their feelings and did not want to give information. For example, a mother described how she was treated by the nurses in hospital when she tried to elicit further news about the diagnosis of her child's condition.

The worst thing was in X hospital. When I got inside to ask about my daughter's condition, the nurses asked me, "Why do you want to ask about your child?" I just wanted to ask about my daughter when she was in the incubator. The nurses kept telling us "24 hours, you want to ask about your daughter, do you think we only work here for your daughter, we have many children here and we have to care for them all" I don't know, probably they were right, but it was not the appropriate way to deal with parents.

Mother of a blind child

Again, the mothers who were working in the health care field paid tribute to the nurses, they described them as being understanding of their worries about their children. For example, one mother, Lila, was a nurse in the hospital where she gave birth, and expressed her appreciation of the nurses who were working there.

I stayed three days in the hospital. My son was born by caesarean. To be honest I got a lot of attention from the nurses, they kept coming to my room from time to time and speaking to me. When they realised my worries about my son, they brought him to me and told me, "Oh look how beautiful your child is" I really appreciated that.

Mother of a child with an intellectual disability

5:2:5 Negative attitudes from health care providers

Concerns about health care professionals were not confined to the initial diagnosis, but also applied to ongoing contacts necessary for the care of the disabled child. Although two parents of deaf children expressed high satisfaction with the behaviour of both hospital doctors and GPs, several other parents spoke about the negative attitudes of the medical professionals they encountered.

I went to the GP two months ago; my daughter had a pain in her abdomen. When the doctor saw her he kept saying, "What a lovely patient we have here, she is beautiful" He played with her. You know he didn't want us to leave. He loved her way of using the sign language.

Mother of a deaf child

In direct contrast, the mother of a child with Down's syndrome described her discomfort with her doctor's negative attitude towards her daughter.

One time we went to the doctor, when he saw us, he said "Ooh, Down's syndrome, Down's syndrome, who is the patient?", as if it was something strange, and he called the practice accountant, "Come and see, there is a Down's syndrome case here!". So what! We are really offended by people staring at our child, it really hurts.

Mother of a child with an intellectual disability

The poor treatment experienced by some parents, such as insensitivity and lack of respect, often led parents to feel they were undervalued. This could become an obstacle which might deter parents from arranging timely care for their disabled children. Reham is the mother of a blind child, who tended to avoid coming to the GP as a result of the negative attitudes of the nurses working there. She stated:

I don't like going to the GP because they've got rude nurses there, I can't understand the way they treat me. You know, one day my daughter had 'flu; I went there to get some medicine. When the nurse saw my daughter,

she looked at her in an inappropriate way and said, "Why is your daughter like this? She looks like a chicken". I didn't create my daughter by myself, Allah creates people and he forms them as he wants. I won't go there anymore. If my daughter has' flu again I will bring antibiotics for her myself.

Mother of a blind child

5:3 Medical diagnosis

All parents actively sought a medical diagnosis for their disabled children. This might help them to confirm whether their children were disabled or not. This section will look at parents' experience of seeking medical diagnoses, examining issues identified through interviewing the parents.

5:3:1 Delays in the diagnosis of the disability

Unlike the parents of children with Down's syndrome, who recognised their child's disability from birth, a number of parents gradually noted the differences in their child's development compared with other children, and their child's problem became apparent over time. This was more likely to be true of parents whose disabled child was not the first child in their family. As their disabled child grew up, they suspected a health problem, which led them to start their journey of the medical diagnostic process. This journey meant going through a series of tests, appointments with different specialists, and results and extra tests. Many parents blamed the paediatricians for their children's situation, as they had not comprehensively checked them after they had been just born. In the parents' view, this led to delays in the diagnosis of the disability. The parent of a deaf child, for example, described how he himself had realized that the child had difficulties, and he felt frustrated that his child had been diagnosed late.

When he was 3 years old, we noticed that when a door next to him was being banged, he didn't pay attention... when we called him, he didn't answer. So, we made an audiogram test for him, they told us that he had severe to very severe hearing loss... When he was born the doctors checked him, but I don't think that they checked his hearing. They told us "everything is alright; he is breathing well, and his weight has reached around 2.5 kilo gm" Then they gave him to us but they never told us that he had a hearing problem; we discovered his problem without any help.

Father of a deaf child

The lack of expertise among health care professionals in dealing with children with disabilities might contribute to delays in diagnoses. Perhaps some doctors tended to be dismissive of the severity of the problem and the need for intensive intervention, and, in some cases, this may have resulted in the child's problem becoming worse. For example, a parent claimed that lateness in identifying his daughter's problem had exacerbated it; he thought that his daughter's problem could have been discovered by the previous doctor at an earlier stage.

The doctor whom we visited later said that it was possible to discover the problem that my daughter had in the fourth or the fifth week after the birth, but unfortunately it was discovered too late, in the eighth week. There was a dereliction which increased the sickness.

Father of a blind child

5:3:2 Movements between doctors

In the course of seeking a conclusive medical diagnosis, one recurrent issue was raised by many respondents. Most parents kept moving between doctors, and reported that – even after receiving an initial provisional diagnosis – they continued to seek opinions from other doctors so as to confirm or overturn the first assessment. The initial diagnosis did not meet these parents' expectations and hopes of having the normal and healthy child that they had dreamt of during the pregnancy. Therefore,

parents clung to the hope of a normal child by searching for a doctor who could either provide treatment for the disability, or tell them that their child had no disability.

Although we were treating our child in the Medical Care Centre, I mean the best doctors are there, but we also went to other hospitals. Unfortunately, they always said the same thing, "Your child's optic nerve is damaged, no treatment available". When we heard about a good oculist, we would go to him directly. I am always thinking that I will find a doctor who can solve the problem. I believe that they will invent a medicine for my child's problem. You know, science is improving every day.

Mother of a blind child

Frankly I hoped to find someone who could tell me, "Your son has no problem or at least his problem is slight". You know we wished we could find a doctor who would tell us my son was normal.

Mother of a child with an intellectual disability

Some parents visited additional doctors because they were dissatisfied with the medical diagnosis provided by the doctor seen previously. This was particularly true among parents who were not given a comprehensive explanation of their child's diagnosis.

To be honest I was dissatisfied with how the doctor had diagnosed him. He (the doctor) didn't spend enough time with him; he just did some checks and asked me some questions. Finally he told me, "Your child has a developmental delay".

Father of a child with an intellectual disability

Within a culture where disability is viewed as something shameful and the birth of a child with a disability is perceived as devastating, it is not easy for the parents of disabled children to accept this new identity. Thus, parents might still wish to believe that they are the parents of a typically developing child, and thus seek extra

diagnoses to support their desired identity. It could be argued, then, that parental movement from doctor to doctor and the quest for a changed diagnosis can be seen as a sign of temporary denial of the disability. This will be discussed later (section 8:2:1).

5:3:3 Lack of understanding and updated knowledge

A few parents had the opportunity to discuss their child's diagnosis with doctors while they were trying to find out about the condition, but they felt that the doctors had not explained the child's case clearly to them. Some parents seemed better-informed about their child's condition than many health care professionals, often due to the fact that they had expanded their knowledge using different sources (e.g. the internet), but their voices remained unheard. This might lead parents to describe the doctor as neither understanding their child's condition, nor being up-to-date in terms of new issues in the medical field.

I took the test results to the doctor, he said to me "Your child has a Fragile X Syndrome" I told him I already know that, I came to you to get an explanation of what that means. To be honest I felt he was unable to discuss this topic. I don't know why they only are interested in prescriptions. Basically he could only search on the internet and explain to me.

Mother of a child with an intellectual disability

Parents tried to find out as much as possible about the precise nature of their child's condition, in order to help them in building a realistic expectation for their future, but the diagnosis often remained unclear. A parent recounted the difficulties he faced when he tried to discover what exactly his son had, and he expressed his anxiety while he was discussing his child's case with the doctors.

I had a feeling that they didn't understand me, for example I was trying to explain my child's case to the paediatrician, he didn't understand what I was saying, I told him about the dyslexia. He said to me "What do you mean by dyslexia? Do you want me to check him up? What do you want me to do?"... I was suffering as I realised that the health care has improved in our country, but there were some areas that needed more improvement.

Father of a child with an intellectual disability

Parents' perceptions that doctors did not understand their children's conditions and had not kept their medical knowledge up to date, must be treated with caution: they may, among other things, reflect wider dissatisfaction with relations with health professionals and perhaps the doctors' poor communication skills. Of course, parents and doctors came to these consultations with different interests and subject to different pressures. While the parents were seeking a comprehensive diagnosis to help them to understand their disabled child's abilities, the doctors' behaviour might reflect routine patterns of working in a busy and under-resourced environment. Moreover, while parents were often concerned with the social functioning of the child, some doctors appeared to operate within a narrow medical model concerned primarily with the identification and treatment of disease processes.

They never understood what I was saying to them. I was aware about what I was saying because I had done some reading on the internet. But they didn't know. When I told the neurologist "my son's comprehension is in a low level" He told me, "The CT scan indicates nothing wrong" The enzyme specialist was the same... He told me "I don't know, but I can give you medicines that would stop the hyperactivity, but it might have side effects" I told him "No, I don't want it"... Because I have searched many times on the internet about my child's problem, I knew better than them. There were studies in Western countries about my child's case and they had no knowledge of these.

Father of a child with an intellectual disability

While the parents were keen to know what their child's problem actually was, doctors were preoccupied with curative medicine and acute treatment within their specialist area and often ignored parents' concerns about recognising what their child had. Doctors might be uninterested in things such as long-term prognosis, prospects for improvement via therapy and education, and the implication for family life and the child's future. This might also explain why some parents mistrusted their doctors and described them as not being understanding during the diagnostic process.

5:3:4 Referral and lack of coordination

It was felt by some parents that, when the doctor was unable to accurately diagnose their child's condition, parents were referred to other medical services. This was deemed by some to be a way of shifting a difficult task that was really the doctor's responsibility onto others. At the same time, parents experienced a lack of coordination between the work of different health professionals. One parent's story illustrates the complex pathways some parents had followed in pursuit of a satisfactory diagnosis:

Some of them (the doctors) referred me to the psychiatric department. When I went to the psychiatrist and sat with him he told me, "What do you want me to do for your son, nothing needs to be treated, your son is accepted socially and his situation is ok". I told him, "My child's case is like this..." He told me, "I don't know, but I can give you medicines that would stop the hyperactivity, but it might have some side effects". I told him "No, I don't want it"... They referred me from the children's department to the neurology department, then we were referred to the brain department, the brain department did nothing, finally we were referred to the psychiatric department... I had a feeling that there was no connection between the specialists; each one was a law unto himself. He might be famous in his own area, but he didn't know other important things related to his topic... The paediatricians recognised that my son had a problem, but they couldn't define what the problem was. They kept referring me to other departments. You know I still go there for health

checks and so far they don't have any idea about the institutions which could support children with disabilities.

Father of a child with an intellectual disability

It is clear that, in this case, the opportunity for professionals from different medical services to work as a team was missed, which affected the coordination of the assessment and treatment process. This, in turn, contributed to the parents' feeling of constantly being referred to new experts, and of a lack of overall support.

5:3:5 Reassurance

Reassurance in this context refers to the idea of there being nothing to be concerned about. In cases where the parents themselves suspected a delay in their child's development, they started their quest for more information by seeking a medical diagnosis. Yet in doing this, several parents complained that the professionals avoided confronting their concerns directly and instead sought to allay their fears about their child developing abnormally. Although reassurance helped ease parents' worries, it often led to late identification of the disability. Some parents described how the doctor tried to reassure them by denying the child's problem.

When Saber reached three, I started noticing the delay in walking and running. His speaking was the most noticeable thing. I started doing medical tests for him at a child development clinic. The doctor told me, "All the test results are normal, there is nothing wrong. Probably his nature is weak. Don't worry, as he grows he will be ok, don't trouble yourself". When Saber reached four years old I put him in a kindergarten. I obviously noticed the differences between him and other children. Then I restarted doing tests again.

Mother of child with an intellectual disability

On the one hand, reassurance might be a kind of relief for some parents as it could keep alive the illusion of being the parents of a normal child, but on the other hand, it

could be a source of stress, as it placed the parents in a position of uncertainty. The reassurance provided by doctors was more credible when it was combined with other sources of reassurance, for example, from close relatives and neighbours or other parents of children with developmental problems who had subsequently recovered. The main risk of this approach was that it could cause a delay in the diagnosis of a disability.

I was too worried about him, but all the people around me, and the doctors who I visited, described me as pessimistic. One of our neighbours told me her cousin was like my son, he hadn't spoken any words before he reached the age of three, and then he became like a radio.

Mother of a deaf child

Parents' perception of their child being disabled was influenced by the medical diagnosis. When the diagnosis was certain, parents would stand a better chance of coming to terms with the disability, whereas when there was no diagnosis, or an unclear diagnosis, parents' perception of their child fluctuated.

5:4 Other issues concerning health care services

Several other aspects of health care services were highlighted as problematic by the parents of special needs children in Jordan. In addition to dealing with health care practitioners and medical diagnoses, the other common issues raised included: following up the child after hospitalisation; costs of medical care services; and giving priority to the child with a disability at hospital and with the GP.

5:4:1 Following up the child after hospitalisation

None of the parents in the study mentioned that a health sector worker had visited them to make sure their child's development was going well, but rather they claimed that if they had not fought for the services by themselves, their child would not have received any attention from this sector. Most parents who had a high level of education talked about the necessity of continuing health checks for the children as they grow older. Some of them described home health visitors in other countries. In one case a father said he could only imagine that he had a health visitor.

We are the only ones tracking our child, no one has asked about my child since he was born. Here in our country, if you don't fight, if you don't insist on healthcare services, if you don't travel from GP to GP or from hospital to hospital, no one will care about you... If I had received a free health care visitor in my home asking about my child, I would have been dreaming.

Father of a deaf child

Unlike western countries, the Jordanian health system makes no provision for services such as Health Visitors who might come to the child's home after the birth, promote the child's growth and development and identify his/her health needs. This limitation of the health care system in Jordan potentially leads to poor programs, which do not achieve the stated aim of early recognition and intervention. Parents told many stories about their struggles to obtain different types of support and service. This will be discussed throughout the remaining chapters.

5:4:2 Costs of health care services

Parents had to face many different kinds of costs incurred in the care of a disabled child. In particular, many were struggling with medical costs. Paying for potential

curative treatment was a big problem for parents of blind children. It seems that these parents were the largest group who reported paying large amounts of money for health services, particularly when they went to the private health sector.

I took my daughter to many doctors and each time I had to have a test, for example the last doctor asked me to have retinal and eye pressure tests. You know I paid more than 200 JD for the test and the doctor; this wasn't the only time I paid a large amount of money. Every doctor we visited we paid a great deal, and yet there is no improvement in Nadia's eyes.

Mother of a blind child

However, though the numbers were smaller, some parents of other children with disabilities also made significant payments. The expense of medical care services was rarely reported by parents with a high household income or those who had full medical insurance.

5:4:3 Giving priority to a child with disability in hospital and with the GP

Some parents in this study were angry that their children were not given special treatment when they visited hospitals and GPs. It was perceived by some parents that health care practitioners should make special arrangements to deal with children with disabilities, perhaps giving them special priority ahead of other cases.

Disabled children should have priority if they have to see a doctor because their parents are struggling to control their behaviour. I mean two months ago we went to the hospital, Zaid was suffering from fever. We had to wait our turn for a long time. I think as Zaid is disabled, they should have let him instantly see the doctor.

Father of a child with an intellectual disability

5:5 Discussion

Interactions between parents of children with disabilities and health care professionals begin from the time parents have their first concerns about their children's health. In this study, findings from analysis of parents' accounts of their experience of health care services highlight three main categories: dealing with health care professionals, medical diagnosis, and a cluster of other issues related to the health care services. The results of this study suggest that Jordanian parents of children with disabilities had poor lines of communication with health care professionals. This is evident from the various stories that parents tell of their encounters with health services, starting from their first suspicions of a disability, and encompassing the passing on of a provisional diagnosis, subsequent clarification and confirmation of the child's condition, and the for information about services.

Many previous studies reported that the parents of children with disabilities were dissatisfied with the process via which they were informed of the diagnosis (Avis and Reardon, 2008; Baird *et al.*, 2000; Dent and Carey, 2006; Hedderly *et al.*, 2003; Huang *et al.*, 2010; Kerr and McIntosh, 1998; Russ *et al.*, 2004). These studies suggested that parents did not receive adequate information about their child, and had little empathy with health care professionals, which in turn negatively affected the process of adaptation to the disability. *"Research has shown that if bad news is communicated badly it can cause confusion, long lasting distress, and resentment; if done well, it can assist understanding, acceptance, and adjustment"* (Fallowfield and Jenkins, 2004, p.317).

During the stressful period when parents had to adjust to the fact of disability, most received neither oral information nor printed materials on support or services. Moreover many parents reported deficiencies in the communication skills of health professionals, which if the accounts are true suggest knowledge deficits, a lack of training regarding the need for sensitivity, and insufficient familiarity with the range of non-clinical services available to support disabled children. Sometimes professionals appeared to operate within a medical model which focused on the disease rather than the child, and formed the professional task as lying wholly within the clinical domain rather than in a wider expertise in matters of child development and social support.

This, in turn, influenced how parents adapted to disability. The study supports the finding from previous research that early experience of communication with health care practitioners has a strong effect on parents. For example, the bad communication style experienced by some of Kearney and Griffin's (2001) participants delayed parental acceptance of their child's disability. Pisula (2011) suggested that the stress that parents suffered when their child's condition was diagnosed, was almost always caused by the inability of health care professionals to provide appropriate support to the parents. This suggestion is confirmed by the data from this research.

According to Kirshblum and Fichtenbaum (2008, p.8) *"Most physicians complete their medical training equipped to provide high-quality technical care but may not be prepared to discuss information regarding a poor prognosis"*. This can definitely be applied to Jordanian physicians when conveying a diagnosis of a disability to

parents, which was often done in an inappropriate way. The professionals failed to provide information and support, which indicates that the medical model of disability was dominant. Kerr and McIntosh (1998) pointed out that when parents receive comprehensive information and advice, they can view the future more positively. The implication of this and other studies is that appropriate guidelines need to be developed and used when health professionals break difficult news to parents (Baird *et al.*, 2000; Choi *et al.*, 2011; Kisler and McConachie, 2010).

Mistrust of health care professionals could be caused by the prolonged diagnostic process, and a failure to provide appropriate information and support, which left parents uncertain and lacking a clear picture of the future. It is expected that earlier diagnosis would lead to early intervention which would consequently improve the outcomes of child development (Fitzpatrick *et al.*, 2007) and decrease parents' stress. This delay in diagnosis of the disability may affect parents' ability to make a right and accurate decision of their child's care and treatment. A further factor that might contribute to mistrusting healthcare professionals was that some doctors tended to dismiss or minimize the parents' worries about their child's developmental delay; those physicians claimed that the child's problem would be solved and disappeared as the child got older. This could further exacerbate the confusion and uncertainty in some families.

For some parents, keeping alive hope of a cure for their disabled child is a vital factor in encouraging an active approach in seeking care, and in assisting them to conquer their negative feelings (Graungaard and Skov, 2006). While parents kept searching

for extra diagnoses, they appeared to be looking for certainty, a sense of control, information, and their lost dreams. Thus these hopes are often unrealistic.

5:6 Summary and Conclusions

There is a certain logic in taking parents' experience of health care services as the first theme for discussion, because parents typically learn of their situation and take the first step in coping with disability in contact with health care professionals, and because this experience often has a lasting impact on them. However, this does not mean that health professionals necessarily provide the main support for this group of parents. Although a few parents expressed happiness with the way in which their child's disability was disclosed, most did not. From many parents' perspective, doctors did not make themselves available to discuss the child's condition and prospects, and some parents reported a deficit in terms of professionals' skills in dealing with this kind of situation. At the extreme some parents believed that their child's disability had been caused by negligent health care, and many more complained about the negative attitudes of such professionals towards disabled children.

Other comments made by parents concerned the medical diagnosis that they were seeking. It appeared that dissatisfaction with the initial medical diagnosis and the wish to keep hope alive pushed several parents to keep moving from doctor to doctor in a search for better news. Yet at the same time there was a feeling of unease on the part of some parents who found themselves referred from specialist to specialist in an uncoordinated way. Whilst it was felt that reassurance was a way of removing

parents' concerns about their child's development, it sometimes led to a delay in identifying the disability.

Finally, parents provided descriptions of other issues in terms of their experience of health care services, such as neglecting disabled children after hospitalisation, the high cost of health care services, and giving priority to disabled children when they went to hospital clinics or GP premises for health care.

Chapter 6: Access to services and support

6:1 Introduction

One recent trend in special education literature is the increasing emphasis on the importance of facilitating timely access to early intervention services for children with disabilities and their parents. It is argued that appropriate and promptly delivered services are crucial at diagnosis or soon after because children and their parents are passing through a crucial period when parents are trying to recognise the disability and meet their child's needs. If this is to be achieved, the pertinent official and non-official agencies collaboratively have to plan and implement a service framework that ensures that appropriate support is delivered to the children and their parents. However, the reality of the situation in Jordan is that a range of different formal and informal institutions are planning and delivering services for children with disabilities in a sometimes uncoordinated, inconsistent and fragmentary way.

This chapter examines several issues in terms of accessing services for young children with disabilities in Jordan. These issues (see figure 5) were highlighted by the parents interviewed: they talked about the educational diagnosis they sought for their disabled children, identifying their purposes and their views on such diagnosis. The public authorities were the prime source of services for most parents of children with disabilities. The parents described: how they had been treated; their feelings; their impressions while they were dealing with such authorities; and how the services were obtained. Finally, different aspects of the available services for young children with disabilities in Jordan were described from the parents' perspectives.

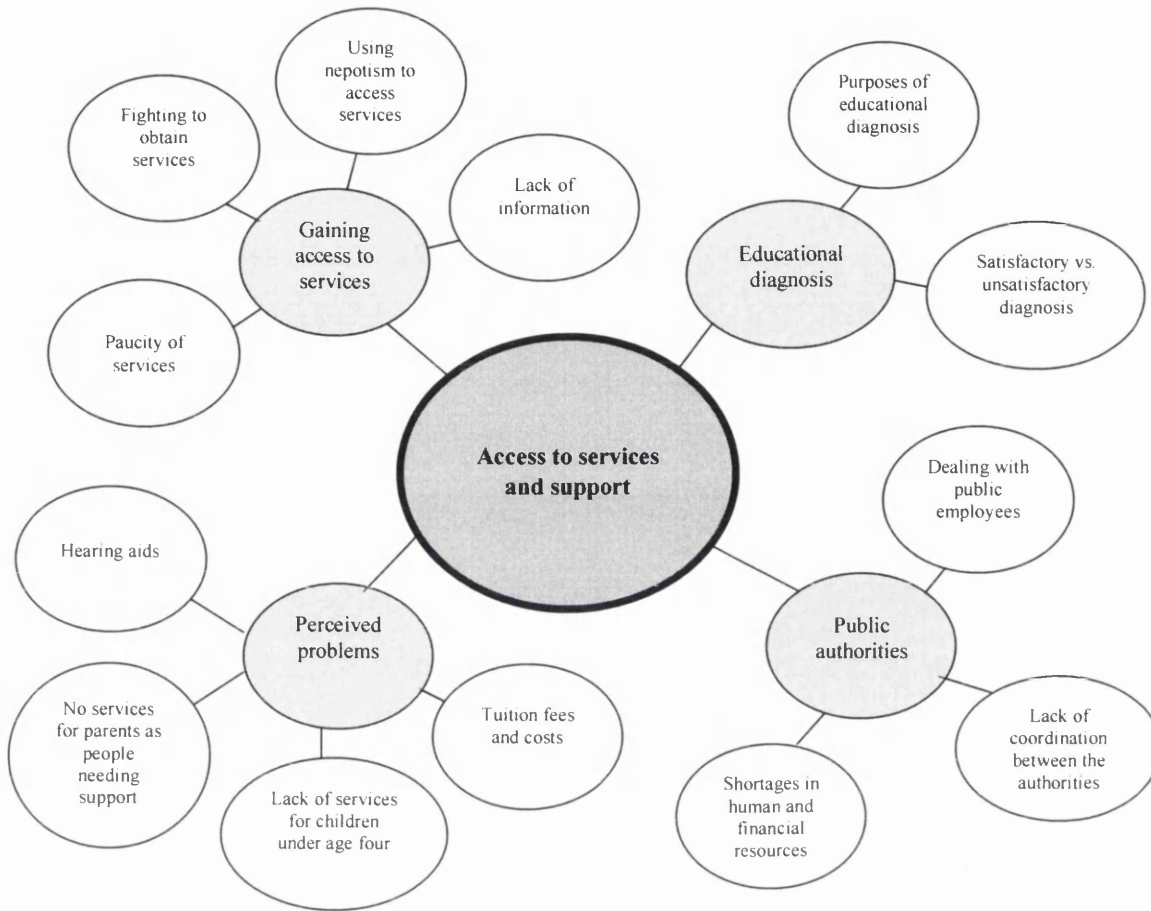


Figure (5): The main categories of response for the second emergent theme, 'access to services and support', including the four subthemes and related categories.

6:2 Educational diagnosis

The concept of educational diagnosis in this study refers to the process of evaluating a child's abilities in different developmental trajectories such as cognitive, social, physical, and linguistic competencies. It could be considered as a sort of assessment of a child's skills, determining what the disabled child can do and what he or she cannot do. However, the process of educational diagnosis is normally required when

a child is considered to have special educational needs resulting from a disability or a developmental delay. This section examines parents' perspectives of the educational diagnosis.

6:2:1 Purposes of educational diagnosis

Most parents in this study endeavoured to arrange an educational diagnosis for their children. Some parents were obliged to have an educational diagnosis of their child undertaken in order to access support from the public authorities, or to enrol their child in a public kindergarten for children with disabilities. The only formal institution that was available for the parents to obtain such diagnosis was the Centre for Early Detection of Disabilities (CEDD) which was administered by the MoH.

One finding that emerged from the interviews was that many parents lacked a clear understanding of what the educational diagnosis entailed. They did not regard it so much as a comprehensive evaluation of their disabled child's abilities, but rather an access key to educational services and support. Although parents had medical reports about their child's disability, the educational diagnosis often functioned as a certificate confirming that the child was really disabled and he/ she was eligible for support and special education services.

I went to the MoSD asking for help, they asked me to bring a report from the CEDD including his diagnosis.

Father of a deaf child

When I came here (kindergarten) the first time, the principal told me "you should go to the CEDD to do an IQ test for your child and bring the report from there".

Mother of a blind child

It was apparent at this stage that some parents still retained hopes that even now their child might be found to be normal, and still sought to defend their identities as ordinary parents of a normal child. Those parents perceived the educational diagnosis as a way of either sustaining their hope, or confirming the medical diagnosis and forcing them to accept a new identity. If the latter happened, parents also found themselves having to attend to new practical questions, including how to find an appropriate placement for their disabled child.

To be honest I went to CEDD as they are the last body who could decide whether Alia is disabled or not. I wanted to make sure that she was abnormal. You know it's human nature to keep hoping.

Mother of a child with an intellectual disability

For some parents, educational diagnosis was a way of gaining detailed information about their disabled child's abilities which might enable them to understand their child's needs. This was particularly common among parents of children with intellectual disabilities especially when they had not obtained a clear medical diagnosis or had been dissatisfied with the medical diagnosis. For example, a couple went to a private centre to gain more knowledge about their child who had been medically diagnosed with a chromosomal abnormality.

One day I had read an ad in the newspaper that there was a centre for diagnosing disabled children. Then I told my husband "why don't we go there? They may be able to explain Farris's situation for us".

Mother of a child with an intellectual disability

Apart from such a comprehensive assessment, many parents have also gained some information about their child's development from an evaluation done in the kindergarten when the child had first enrolled. The assessment in the kindergarten

appears to have been presented to parents as a way of diagnosing a child's abilities in different domains, which might help in setting an appropriate curriculum for the child.

When I went first time to the kindergarten to enrol Samar, they diagnosed him; they evaluated his physical, social, and language skills. I think they also did a short cognitive test.

Mother of a blind child

6:2:2 Satisfactory vs. unsatisfactory diagnosis

The parents' views on the educational diagnosis that had been done for their children were probed in the interviews. There were mixed views, with rather more parents dissatisfied than satisfied. Parents of children with intellectual disabilities commented on the educational diagnosis more than the other parents did. They mentioned concerns about such issues as the speed of diagnosis, the instruments used, the professionalism of staff, the cost, and the results. Some of the parents highlighted more than one aspect of the educational diagnosis process. Examples, and the number of parents who made comments, are shown below.

Five parents commented on the speed of the diagnosis undertaken in the CEDD.

You can't imagine how rapidly he diagnosed him. Within ten minutes he had finished the test.

Mother of a child with an intellectual disability

Seven parents commented on the instrument that had been used for diagnosing their children's skills and abilities.

Honestly, I wasn't convinced with the diagnosis, because they used outdated and inaccurate tests. I think I could make up tests at home that are better than their tests.

Mother of a child with an intellectual disability

Six parents felt that the professionals who had done the diagnosis lacked sufficient qualifications or competence for this task.

Candidly, the professional was not organised. I think he needs more training in using such tests with deaf children. He couldn't determine Rola's needs and abilities.

Father of a deaf child

The cost of educational diagnosis was mentioned only when the parents sought it from a private specialist. However, this issue of cost was sufficiently important that it was reported by twelve parents.

I will not let them use me or my daughter as a tool to test their abilities. We did one test in a private centre, it cost 100 JD. The test was just questions and answers from a form! And he was just checking true/false. I wondered, because I can print this form myself from the web and do the test for my child. The problem was that the questions were in English, and they translated it wrongly.

Father of a child with an intellectual disability

Two parents were unconvinced about the results of the educational diagnosis; they thought that it was misleading and perhaps deliberately inaccurate. For example a parent was unconvinced about the results, as he suspected a commercial purpose behind the low scores. He said:

Frankly, the reports weren't convincing. All of them. Particularly that one from the private centre who gave me a report including his abilities in different skills. They underestimated his abilities. You know, why did they do that? To make me feel that my son was in need of their services, such as speech therapy, occupational therapy, and physiotherapy. This would allow them to ask for extra fees.

Father of a child with an intellectual disability

There were hints in the interviews that some parents were still struggling to accept their child's disability and their new identities, and one may infer that this made it difficult for them to accept any diagnosis of disability. Parents' difficulties in acknowledging that their child was disabled seemed in some cases to lead to a constant quest for a new diagnosis.

I swear, no one was able to give us a comprehensive report about my child's case. Neither doctor nor specialist could give us a full diagnosis. The last one I went to, he had some geometric shapes and some pictures, and then he started questioning my child... Do you think these tools can determine my child's abilities? So far I'm still looking for a specialist who could tell me what my child's condition is or even sort it out.

Father of a child with an intellectual disability

Without exception, all parents of the blind children were happy with the initial educational diagnosis that had been done in the kindergarten. Apparently, those parents tended to compare the kindergarten's diagnosis with the CEDD's diagnosis which some of them had felt dissatisfied with. Also the kindergarten's diagnosis might provide to the parents more information about their children, particularly regarding positive points.

I can't understand how he diagnosed her in the CEDD; He looked at her, and asked her "what's your name?" She replied "my name is Muna" Then, he said: she is good, and then he gave me a report to hand in to the kindergarten. But when I brought her here, they evaluated her language, physical, and social abilities. They asked me many questions. Everything you could imagine they asked me about. Their diagnosis was logical. I was very satisfied with it.

Mother of a blind child

Arguably, for those parents the educational diagnosis was the first opportunity for them to feel that they were involved in the diagnostic process through taking into account their views on their children's abilities. This supports the idea, which is

frequently reported in the literature, that parental involvement would ultimately increase their satisfaction with the services. The question of how far the parents were involved in the services provided to their disabled child is examined in the next chapter (section 7:3).

6:3 Public authorities

In Jordan like most countries, the public authorities are usually responsible for children's well being. Thus, in this study, most parents of children with disabilities sought help from these authorities after their children's disabilities had been realised; they resorted to different public authorities that might provide support. The MoSD, the MoH, and the HCAPD were the three public authorities which were identified from the parents' experience of seeking support and services. The staffing, capability, and coordination of these various authorities are three issues that were highlighted by parents as problematic when they sought services for their children.

6:3:1 Dealing with public employees

Most parents in this study sought support from public authorities. In the research interviews they looked back on their experiences to tell the story of their dealings with public employees. Many parents were unhappy about how staff had treated them. While a very few parents told positive stories about how they had been treated, others tended to describe bad experiences. A handful of parents reported that communication with the public authorities was good, but many others complained that their requests were not answered. For example a parent went to the MoSD

asking for support; he was happy with the politeness shown, but he did not achieve his aim.

They told me "you're welcome and how can we help you?" They let me say what I wanted. Then, they asked me to have a seat, and gave me an application form to fill in. Finally, they told me "your application is ready, we will call you" They were polite, but they never called me.

Father of a deaf child

Apparently, communication with such public organisations often fell short of parents' expectations. Although some of the employees tried to empathise with the parents, they unintentionally caused offence. The parents reported that the employees felt pity for their children.

I went to the HCAPD as I had heard that they would support blind children. When the worker saw my child, she told me "Oh, may Allah be with you". To be honest she wanted to empathise with me but she annoyed me.

Mother of a blind child

Many parents expressed negative feelings about their dealings with public employees. They experienced a sort of humiliation and belittling. For example, some parents claimed that staff treated them as beggars, while they viewed themselves as clients seeking professional support.

They thought we went there because we wanted to beg on our child's behalf, but I told him "I know what you're thinking. I didn't come to beg for money; I'm not here to beg for my child. You are a governmental institution and you should help my child".

Mother of a child with an intellectual disability

Also, some parents claimed that when they went to the public authorities seeking services for their children with disabilities, the employees evaded them by passing them on to different employees and departments.

It is a fact that if you want to go to the MoSD, you will be kept moving from one office to another. The first employee I met there told me to go to the special education department, and then they referred me to the assistance department. Then, they told me "your application isn't our responsibility".

Father of a deaf child

A significant number of parents felt angry as services were promised to them, but the services were not delivered. It is possible that the regulations of the public authorities did not allow all the parents to receive support, and at the same time some parents did not accept these regulations, which led them to ask constantly for the services. Consequently, the promises given by the public employees might be a way of dismissing the parents without meeting their needs.

I went to the MoSD, I told them that my son should join a school or a kindergarten; they told me "we don't provide services for such cases, and we can help only handicapped people and widowed women". Then they asked me to go to the HCAPD, I went there several times to apply for support. They told me they would give support by paying a part of my child's fees. I waited more than a year and again we didn't get anything. They didn't support us or do anything for us.

Father of a deaf child

Overall parents' dealings with public agencies exposed a gap between expectations and the unpleasant reality of poor service. Parents expected to be treated honestly and sympathetically by staff, but their experience of problems often led to a breakdown of confidence, which in turn contributed to feeling of frustration, depression, hopelessness and stress.

6:3:2 Lack of coordination between the authorities

Many participants complained about a lack of coordination across the public authorities responsible for supporting children with disabilities, which appears to be one of the main perceived problems with the framework of services in Jordan. Poor co-ordination could lead to tension or conflict between agencies, which led to difficulties in accessing the appropriate services.

The HCAPD is a separate body, so there is a lack of co-ordination. The MoE believes that the HCAPD has interfered in their duties and the MoSD believes that the HCAPD has taken over their responsibilities. I mean there is no coordination between them, 'Everyone is singing and dancing individually'.

Father of a child with an intellectual disability

The lack of coordination meant that a parent seeking help for the first time had to make sense of a complex mosaic of service provision, without a map or knowledge of the rules. For example, parents were not allowed to receive support from more than one authority at the same time. To prove that parents were not already receiving support when they approached a new agency, they were required to tender an exacting collection of documents. As there was no coordination between the public authorities, the parents felt that the procedure of providing such documents was difficult. Also some parents claimed that collecting evidence to show their eligibility to receive services was far from straightforward.

I told them "I'm a normal employee and this is my salary slip". But they told me "No, you have to bring to us papers to prove that: you are not taking any assistance from the MoSD or the HCAPD, you don't own a car, your wife isn't working, and you don't own land". I mean you can't imagine how many documents they asked for. You know, these days we

are in the computer era, which means that by clicking one button you can access all my documents.

Father of a deaf child

Various services were needed for children with disabilities and their parents, and this required an integrated and collaborative approach to deliver an effective system of services, but unfortunately there was little collaboration between different Jordanian agencies. Also, it appeared that there was no individual authority whose services were sufficiently comprehensive to meet the complex needs of children with disabilities and their parents.

6:3:3 Shortages in human and financial resources

In Jordan the public authorities involved in disability services suffer from shortages in human resources and funds. For instance, the professional workforce is very small, so that staff have to do much work with few resources. This is compounded by the lack of coordination, and involvement of unqualified staff which may result in inefficient and limited services. These deficiencies often lead parents to feel unsupported:

The HCAPD is still developing as it is just established, and I think it will have a considerable role in developing special education services. However, my son's school has never been visited by any staff from the HCAPD. A few days ago I met some of the HCAPD's employees I told them "why do you keep asking me about the level of services in the school? Why don't you visit it?" Their resources are still limited - particularly human resources - and they told me that "we don't have qualified staff".

Father of a child with an intellectual disability

From the interview responses, it seems that the less-than-optimal services provided by the public authorities have had damaging consequences for their reputation: their

employees were not always seen as competent; they had limited resources; and access to services depended on being able to navigate a way past complex entry procedures. Consequently, many parents tended to avoid trying to access the services provided by the public sector.

Also the MoSD's centres have a bad reputation, I've heard that their level in treating and educating disabled children is bad... probably this was wrong but I don't know.

Father of a child with an intellectual disability

It should be noted that there were additional factors that induced some parents to refuse to access the services that were offered by the public authorities; these factors will be discussed later (section 8:4:3).

6:4 Gaining Access to Services

When educational assessments had been completed and parents had fuller knowledge of the nature of their child's disability, the next step for most was to try to find out what services were available for them and their children in their local communities. Many respondents reported obstacles or difficulties which might deter them from searching further and ultimately prevent them from receiving services.

6:4:1 Lack of information

One crucial prerequisite for getting in touch with appropriate services was information about their location and how they could be accessed. Information would help parents to obtain the necessary services and benefit the children. However, almost all parents in this study reported a big gap in consistency and reliability of

information provided. The inadequacy of information and the desirability of improving it, were constant themes in their interview accounts.

I wish I could find information guiding me where the services were and how to access it. You know when we knew our son is deaf, we didn't know where to go, and we didn't know if there was a kindergarten for such children. I found out about the kindergarten and the HCAPD by chance.

Father of a deaf child

All the parents reported a paucity of available information; with different information gaps evident at different stages. They wanted information from the first time they suspected the disability right through to the stage at which respondents were interviewed. As mentioned above this extended from the initial need to know what the disability meant and how to deal with their child – a constant preoccupation for parents who had never be expected to be in that situation – through to finding out how to access services.

Let me tell you that, I've never heard that there is an agency or a site offering information about any kind of disabilities. If you got a disabled child, you would have to depend on your personal experience. No one will tell you how to treat your child or where to find support and school for him. You have to find out by yourself.

Mother of a child with an intellectual disability

Because the pertinent information was absent, the parents faced problems in accessing the available services. From the interview accounts, it took a great deal of effort to build up a picture of where they could find formal support and arrange services.

If I wanted to evaluate the availability of the information, I would give it less than 10%; there wasn't any information. One time I had a discussion with a number of policymakers working in the HCAPD, I told them "you

are representing the main public body supporting disabled people. Where is your role explained in the media? We don't see your announcements, you sometimes run seminars, workshops, and some activities, but the most important thing is the announcements via newspapers, radio, and TV. What is your role? I want to know what my son's problem is through your agency". If there was enlightenment about disabilities, I would know what my child's condition is.

Father of a child with an intellectual disability

While some parents had access to the internet, they also complained about the absence of the relevant information online. There were few Arabic-language website and most parents had little idea where to begin their search. Again some blamed the government for its tardiness in addressing this gap.

Actually, there is much negligence regarding this issue. For example, we've got the internet at our home, we looked for something to guide us where to go, or what to do but we found nothing. We found a lot of American, British, Russian, Spanish and Polish websites and most of them are in English language. We didn't find any Arabic site about Down's syndrome. When you face a problem in your country, you start looking for solutions, but here there are none.

Father of a child with an intellectual disability

Lacking the information about the available services and support would make accessing the services more difficult for the parents and pose more challenges. This in turn reinforces their feeling of frustration and lost their control of their situation.

6:4:2 Using nepotism to access services

In this study, nepotism refers to receiving services and support based on having a contact or good rapport with someone who is in power. In light of lack of a clear path for gaining access to special education services, searching for an influential contact or sponsor was seen as an effective way, from the parents' perspective, of obtaining

support and services. Eleven parents indicated that nepotism helped them in accessing the services.

From my experience, I had applied for support through the HCAPD, they didn't reply. I called them many times and the thing wasn't sorted. My husband had a contact in the HCAPD, he called him. Then, they helped us with our son's tuition fees; they paid two instalments to the kindergarten.

Mother of a child with an intellectual disability

One of those eleven parents said that without a personal contact he could not have accessed the desired services.

If you want the truth, without the nepotism you can't get the services. Impossible.

Father of a deaf child

Another parent went to great lengths in his interview to describe how he had gained entry for his child without relying on nepotism. This seemed such an unlikely story that he felt compelled to swear that it was true.

Regarding the HCAPD, as it is the umbrella organisation for all people with special needs, I got support from it. Wallh (I swear) I didn't rely on nepotism to get that support. Basically, I applied for financial support, and after one month I went there when I was told that I was accepted.

Father of child with an intellectual disability

6:4:3 Fighting to obtain services

Although receiving special education services is a legitimate right for children with disabilities, some parents in this study felt that they had to fight to obtain the services. For example, a father talked of his 'battle' to obtain the services he wanted.

We had been told that we could have a hearing aid for Reem from the MoH, I went there asking for it. They told me "your daughter isn't eligible to have a hearing aid". I shouted in his face... "Why isn't she eligible? I want to see your boss". After a long discussion with the boss, I got the hearing aid. You know, if you didn't battle for the service, you wouldn't have it.

Father of a deaf child

Often it seemed that the lack of a clear process for applying for a service forced parents to use unconventional means and make extra efforts. Some parents reported that they had to 'chase up' the public authorities many times in order to get the desired services. Things like special instruments or therapy would not been delivered unless the parents constantly pushed staff in the public agencies.

I filled in the application and submitted it to the office. They told me that they would call me, but they didn't. After two months I went there, they told me "don't come here we will call you". But they didn't. I kept phoned him every other week. Finally, after four months, they told me that the Braillewriter was ready to collect.

Father of a blind child

6:4:4 Paucity of services

Generally, most parents indicated the inadequacy of the available services in the public sector, when set alongside the number of children with disabilities. This was notably true in terms of the services offered to the children in the preschool age group. There were very few specialist kindergartens for children with disabilities run by the MoE and MoSD, and only a few run by the voluntary sector. Further, these kindergartens that existed were mainly in Amman, the capital city of Jordan.

Don't tell me you don't know the situation here. As you know, for deaf children there is only one kindergarten in Amman. God be with people who live outside Amman, I'm wondering how they educate their children.

Father of a deaf child

As a consequence of the small number of kindergartens which offer services for children with disabilities, most parents had little or no choice about where to go, which led to considerable frustration.

In other Arabian countries, they envy us because they think we are developed in the field of special education. They don't know that we don't have choices where to educate our child.

Father of a blind child

Given the shortage of specialist provision, many parents tried to enrol their child with disability in the ordinary kindergarten. This was something they approached with trepidation, as few of these facilities would agree to register children with disabilities. Ostensibly this was generally because of the lack of specialist facilities and the necessary environment for this group, but some parents also suspected that a degree of stigmatisation and discrimination was involved.

I have tried to put her in the kindergarten near our home. I can't understand why they were adamant in refusing her, even though I offered extra money to them.

Mother of a child with an intellectual disability

Excluding children with disabilities from enrolling in mainstream school settings could be seen as a form of discrimination, which led to unequal treatment of children with disabilities within the educational system in Jordan. This may be, in part at least, a consequence of conceptualising disability from a medical perspective rather than in terms of a social model that assumes that disabled children should be given a place in normal settings. This early segregation appears likely to be a significant barrier to later integration and normalisation of disabled adults in Jordanian society.

6:5 Perceived Problems

Regardless of the sector providing special education services, parents were generally dissatisfied with what was available for young children with disabilities in Jordan. The parents talked about several areas in which the available services were deficient, including various barriers which hindered access or uptake of services. Among the different aspects of the available services that respondents mentioned were the cost of the services; lack of services for children under age four; and absence of services offered for parents themselves. There seemed to be particular problems, in the case of hearing-impaired children, concerning the availability and reliability of 'hearing aids'.

6:5:1 Tuition fees and cost of the services

The disability services provided in Jordan were offered by three sectors; the public sector; the private sector; and the voluntary sector. Parents whose children received services from the public and voluntary sectors were fairly satisfied with the fees that they paid. On the other hand, the parents buying services from the private sector were highly sceptical about value-for money. Some parents came close to describing the private special education facilities as commercial institutions motivated only by profit.

I still believe that they are charging very high fees. We are paying 500 JD a month to the kindergarten. I believe that university student don't pay that's amount for their fees. Do you think the services they provide cost that amount of money? I don't think so.

Mother of a child with an intellectual disability

Many parents believed that the absence of governmental control of the private special education centres was the reason behind the high fees charged; there were neither governmental regulations nor active supervision of tuition fees in the private sector. These centres were seen by many parents as money-making enterprises rather than educational and human service organisations.

All special education centres, I mean the private centres are asking for high payments. Each one of them has its own price. They can increase it as they wish. No one would govern it.

Father of a child with an intellectual disability

Not only were the basic tuition fees high, but there were also charges for additional services like speech and language therapy, occupational therapy, and physiotherapy. It was perceived by parents that such special services were grossly underprovided by the public authorities – if not absent altogether, so the parents had to turn to the private sector to get them.

We started searching for someone who could teach him how to speak; the lowest price we've got was 10 JD for each session... And the session from them is only 45 minutes, not a whole hour, and you need to send him and bring him back from there yourself.

Father of a deaf child

6:5:2 Lack of services for children under age four

Only five parents in this study reported that their children had received services before they enrolled in kindergarten. The majority of parents reported a virtual absence of services of children under the age of four years. Accessible early intervention programmes seemingly did not exist.

When I heard there was a kindergarten for blind children, I went there straight away. But unfortunately they told me “your child is still too young, we don’t accept children under the age of four”. This is unfair as the first four years are the most important age for children. My child lost four years. This is a big issue. I wish I could make this public knowledge and influence public opinion to change this.

Mother of a blind child

Even the services delivered to the few lucky children before they had enrolled in the kindergarten were unsatisfactory from parents’ perspective. Contact time was less than an hour per week, and in this study consisted of a form of home visiting provided by a Portage programme team. As a parent stated:

Because the child didn’t accept the specialist, the time she spent with Samar didn’t help. She needed more time to start interacting with the specialist - what the specialist was trying to teach within the limited time provided. We were doing very well with Samar after the specialist left. For example, the specialist spent one and half hours to teach Samar how to throw the ball and Samar didn’t learn even to catch it. When the specialist left, Samar started to catch the ball and play with it.

Father of a child with an intellectual disability

6:5:3 No services for parents as people needing support

Although the special education literature often emphasises that early services should consider the needs of the whole family, the parents in this study reported a major deficit in this area. None reported securing access to services that were specifically designed to address the parents’ as opposed to the child’s needs.

We never received services for us as parents. I wish we received at least information about the disability, particularly when Khalil was born.

Mother of a child with an intellectual disability

From the field notes that had been taken after each interview, some parents mentioned that they lacked the opportunities to discuss their child's problem with anyone, or talk about their own feelings and situation. The parents stated that the interview was the first chance for them to talk about their disabled child, and several expressed their happiness for having such opportunity. This can be linked to parental needs for support and its influence on coping with disability which will be discussed in chapter eight.

6:5:4 Hearing aids

Most parents of children with hearing disability commented repeatedly on issues regarding the hearing aids. They described numerous problems in obtaining and using the hearing aids. The aids were difficult to obtain and even when they were promised there were often long delays before they were received.

We have been told that our son needed hearing aids to use them in both ears, so I applied for two hearing aids from the MoH. After two years we received one, that means, we needed another one for the other ear. They told us "We can't offer more than one as there is a huge demand on the hearing aids". So we had to buy one from our own pocket.

Father of a deaf child

It was generally agreed among parents of deaf children that the hearing aids which were provided by the public bodies were of low quality. Some aids worked only for a limited time, so that equipment failure might force the parents to buy new aids or look for other options.

The aid that was provided by the MoH is of such poor quality. It stopped working after three months.

Mother of a deaf child

A considerable number of parents of deaf children experienced a great challenge in helping their children adjust to the hearing aids. The deaf children did not receive any training related to using such devices. Also, the parents were not being guided to help children in doing so.

No one trained him or even told us how to turn it on. We started turning it on and off. You know Malek had a lot of trouble when he started using the aids. The aids are very sensitive; it maximizes all the sound around. He kept taking them out of his ears.

Father of a deaf child

Some parents faced with long waits for the aids eventually opted to purchase them from their personal funds. Almost all those purchasing aids privately complained about the high price.

I had waited for six months after I applied for the aid. Then I bought it from my own pocket. I really shocked when I found out the price. It was 560 JD. Do you believe that? But what can you do. I had to buy it.

Father of a deaf child

The cost of hearing aid batteries and the problem of maintenance were also highlighted by some parents. There were real issues of affordability for some parents, especially when such services were not offered by governmental agencies. For instance, a father described how it was difficult for him to afford a repair his daughter's aid.

But repairing it is very difficult; there is only one shop who can fix it. One time I went there, they asked me to pay a large amount of money, sometimes they asked me to pay in dollars... So far I'm still suffering from this problem. This problem is accompanied by supplying batteries which are expensive and only last for a limited time.

Father of a deaf child

6:6 Discussion

Generally speaking Jordanian parents found accessing services for their disabled children to be a complex process. The main problems lay in the areas of access to necessary information regarding the available services and its applications, dissatisfaction with the way that parents were treated by public agencies, and the limited scope of available services and support, including the absence of any specially targeted support for parents themselves.

There was little consensus amongst respondents about what educational diagnosis entailed. For some parents it represented a confirmation and validation of their child's disability and their identity of being parents of a disabled child. For others, it was seen as one more source of information about the disability and their child's abilities which might enable them to better understand their child. Without educational diagnosis, some parents would not be able to access services and support from public authorities, so it was also seen as a certificate that would allow entry to services. However, a majority of parents were dissatisfied with aspects of such diagnosis including the way in which it was conducted, the limited competence of practitioners, shortcomings in the test tools, and the high cost of assessment.

Rodger *et al* (2008) state that the low satisfaction with services expressed by her participants was caused partly by their poor relationships with programme facilitators; the professionals did not value the mothers nor sustain their feeling of competency to care for their children. Parents in the current study experienced unsatisfactory treatment from different professionals including healthcare professionals (see the previous chapter), public authority staff, and kindergarten

teachers (see the next chapter). These shortcomings in the service provided may be stemmed from the professionals' perceptions of disability and their attitudes towards disabled children and their parents.

Carpenter (1997, p.175) writes that "*The families of children with special educational needs do not seek sympathy, do not want to be patronised. They do want to be valued and treated as equals*". This is the core concept of family-centred model in delivering services for children with disabilities which insists on the need for collaboration and cooperation between service providers and parents of disabled children, including open communication, mutual understanding and respect (Brett, 2004; Dunst, 2002; King *et al.*, 2004; Wade *et al.*, 2007). Unfortunately, services for Jordanian children with disabilities do not meet these requirements; few choices or opportunities to make decisions about service use and support were available for the majority of parents in this study.

Although the Jordanian government has altered the disability legislation and its provision for children with developmental delay (see section 2:4:1), there is still significant inequality of treatment when compared to the services provided for other normally growing children. Parents of non-disabled children do not experience the same difficulties in accessing services reported by the parents of disabled children in the present study. The marginalisation and exclusion of children with disabilities and their parents is all too evident in Jordan. Parents have few opportunities to share in consequential decision making with service providers (Brett, 2002; Case, 2000). The professionals in the public authorities controlled their relationship with parents and had power as public employees to control events. Of course the literature shows that

this is not unique to Jordan and many parents in other countries report similar difficulties in accessing services for their disabled child (Crabtree, 2007; Crawford and Simonoff, 2003; Paradice and Adewusi, 2002; Rodger *et al.*, 2008). These experiences include referring parents 'to and fro' between professionals; lack of sharing of information; lack of specialists; and fighting to obtain services. These findings were echoed in this research.

The complicated nature of services and the obstacles that stopped parents getting help often left them feeling dispirited and even oppressed by their child's disabilities (Brett, 2002). From parents' reports professionals often treated them badly. In Jordan at least the medical model of disability remains highly influential, with negative consequences for the way parents and children are regarded (Brett, 2002; Case, 2000). This is a major factor that has blocked any shift towards a family-centred model of service delivery (Dunst, 2002; Dunst *et al.*, 2007; Wade *et al.*, 2007; Whitaker, 2007).

Although several studies have shown that early intervention services can enhance children's development in the earliest years of life (Carpenter, 2005; Doyle *et al.*, 2009; Karoly *et al.*, 1998; Reynolds, 2004) and that services are more effective when delivered early, most parents in this study claimed that their disabled children had not received services before the age of four. Equally important, though many commentators argue that these services should target the whole family of the disabled child (Bailey *et al.*, 2004a; Carpenter, 2005: 2007; Kagitcibasi *et al.*, 2001), respondents in this study had found no services organised specifically to support parents. This may suggest that the significant benefits of early intervention services

for children with disabilities and their parents have not yet been realised by the stakeholders and decision-makers in Jordan.

The study shows that nepotism or at least attempts to gain advantage by getting powerful friends to pull strings on one's behalf so as to access services and support, are common in Jordan. Indeed some respondents said this was the only way to get services. This suggests that not all parents have equal access, and that the better connected always have an unfair advantage.

6:7 Summary and conclusions

In conclusion, this chapter has set out to explore the parental experience of accessing special education services, understanding their views on different aspects of the available services, and examining the assistance available to parents and their children with disabilities.

The findings suggest that although some steps have been taken improve access to services for children with disabilities in Jordan, the parents still complained about many significant barriers or gaps. Educational diagnosis for children with disabilities was a major focus for parental dissatisfaction. Parents were forced to seek an educational diagnosis because it was a necessary pre-requisite to access certain services, and also because it might provide confirmation of the disability and other information. However, the majority of parents remained dissatisfied with service provided by both public or private sector organisations.

Most parents sought to access public services first, but many expressed dissatisfaction with the quality of the services provided. From the parents'

perspective there was a lack of coordination between the public authorities as well as shortages of human resources and funds. Access to these facilities was hampered by a lack of accessible and relevant information. In order to receive the available services, a number of parents had to resort to nepotism and others had to battle with providers.

Unlike the parents whose children were enrolled in a public or a voluntary setting, the parents whose children were enrolled in a private setting were unhappy with the cost of the services. The lack of services for parents and for children under the age of four was a particular source of dissatisfaction for some parents. The parents of deaf children experienced special problems in obtaining, using and maintaining hearing aids.

Chapter 7: Kindergartens for children with disabilities

7:1 Introduction

In Jordan, special education services for children with disabilities aged four to six are mainly provided via kindergartens. Many of these institutions are funded by the MoE, the MoSD, and the voluntary sector; however, a number of kindergartens, particularly those serving intellectually disabled children, are managed and supervised by the private sector. The services offered by special-education kindergartens are called early intervention programmes or special education programmes.

Since classroom teachers and kindergarten principals were identified by parents as the major service providers of early intervention programmes, this chapter examines the ways in which parent-teacher relationships and the kindergarten environment affect parents' involvement in their children's education (see figure 6). First, this chapter analyses the relationships between parents and staff at special-education kindergartens, and then discusses parental involvement in education. An examination of parents' opinions of the kindergarten environment follows. The chapter concludes by discussing the effects of the preceding factors on parents and disabled children.

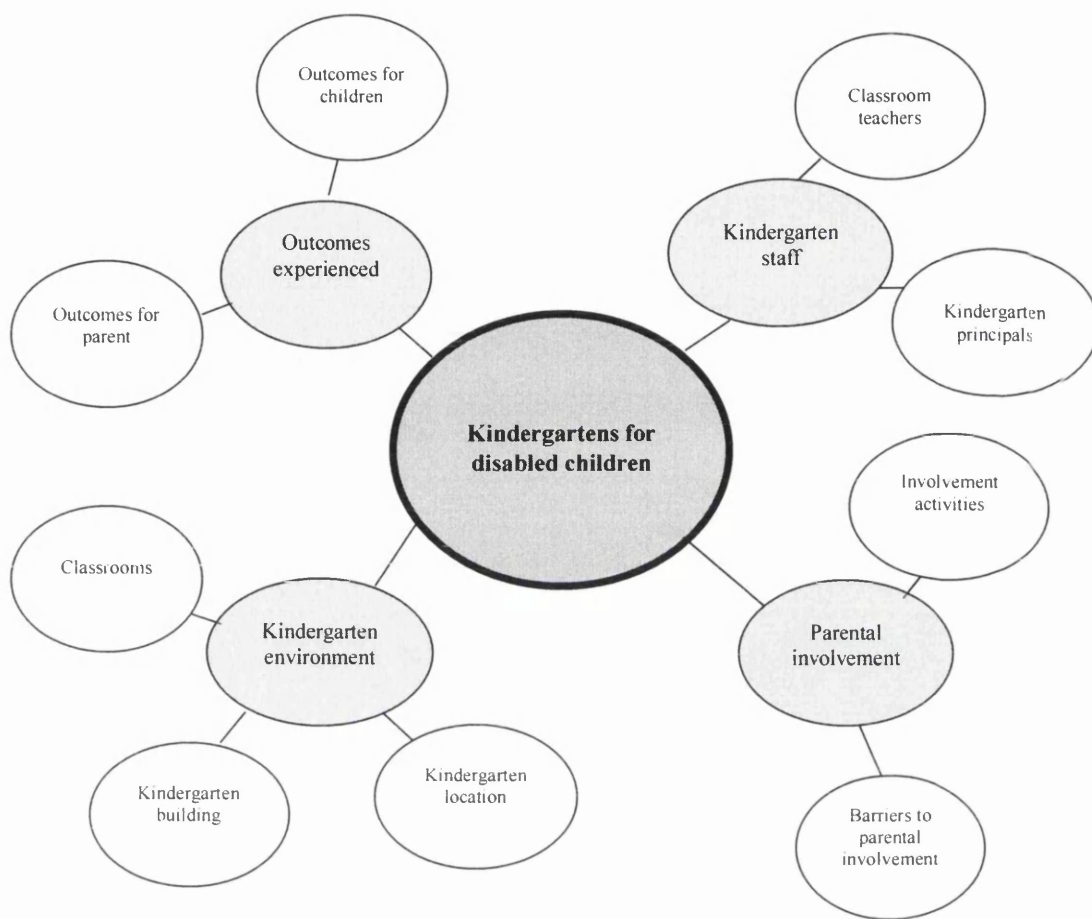


Figure (6): The main categories of response regarding kindergartens for children with disabilities, including four subthemes of response and related categories.

7:2 Kindergarten staff

When participants in this study talked about their relationship with kindergarten staff, they split the staff into two groups: principals and teachers. Participants mostly recounted their experiences with teachers and spent less time talking about their

experiences with principals. These recollections revealed that ongoing communication between parents and staff was mainly oral rather than written.

7:2:1 Classroom teachers

As previously mentioned, parents perceived classroom teachers as the main service providers for disabled children in kindergarten environments. When talking about their communication and satisfaction with teachers, the majority of parents seemed to value their relationships with the classroom teachers and expressed respect for their roles and views (an attitude that did not always extend to other public-sector employees). More importantly, most parents stated that the classroom teachers were unconditionally accepting of their children.

From my experience with this kindergarten, the classroom teacher is so kind. When I call her [the teacher], she keeps welcoming me. She loves Ibraheem so much. She always cares for him and pays a lot of attention to him.

Father of a deaf child

However, the parents interviewed also claimed that despite being polite, teachers often ignored their opinions and did not take their recommendations about the learning process into account.

Honestly, my child classroom teacher is a very polite person. He always listens to my notes and my suggestions. But, you know, he rarely implements what I've said to him.

Father of a child with an intellectual disability

The parents whose children were in private kindergartens tended to praise the classroom teachers more than those parents whose children were in public kindergartens. These parents described their children's teachers as respectful,

supportive, positive, sensitive, and friendly. This disparity can likely be explained by the fact that private kindergartens receive most of their funding from their students' parents. As a result, the heads of these kindergartens may caution their teachers to treat parents carefully and respectfully.

An association between children's development and parents' satisfaction with teachers was visible in these interviews. Parents who reported low improvement in their children's skills were more likely to be dissatisfied with classroom teachers. For example, one parent stated:

My child has been in the kindergarten for more than one year and I don't feel he is improving. So far, he can't say a sentence clearly or even count to number twenty. I don't know what the teachers are doing in the classroom. I went there one day and I told them, 'I don't want my son to learn sign language; I want him to learn speaking'. They didn't respect my opinion.

Father of a deaf child

While the majority of parents were happy with teachers' efforts to educate their children, a few claimed that the teachers were unqualified and had insufficient knowledge of new learning methods. For example, Reham, the mother of a blind child, criticized Jordanian teachers for not using modern methods used to educate blind children in other countries:

They aren't well qualified. For example, the best teacher [they have], who has been working in the field for fourteen years, has just started using touchable models when she tells a story. I think that they don't have the ability to communicate with people who have experience outside of Jordan. For example, in Saudi Arabia there are much better programs, such as computer programs.

Mother of a blind child

Another problem raised by most of the parents interviewed was that the teachers kept changing. They stated that their children had had good relationships with their previous teachers, and when those teachers were replaced the new teachers had to establish relationships with the children, which took more time. Parents also mentioned the issue of qualified teachers emigrating to other countries in pursuit of higher salaries. Additionally, parents noted that most new teachers were newly graduated and had no practical experience of teaching disabled children.

The teachers keep changing because there are disagreements about salary. When the salary of the teacher goes up, they release him and then they hire a new one with limited experience. I saw well-qualified teachers travelling to the Gulf countries, particularly to Kuwait, so we lost them. I mean they went to other countries because the centre didn't pay them a good salary. Nowadays, most teachers in my child's centre are new graduates... This is a big problem; those teachers are new faces with limited experience.

Father of a child with an intellectual disability

7:2:2 Kindergarten principals

For most parents in this study, the first staff members they encountered at their children's kindergartens were principals. Some parents only interacted with principals during the kindergarten registration process; thereafter, the kindergarten teachers were their main school contacts. Unlike teachers, principals were not directly involved in the process of educating students.

All parents in this study had contacted the principals of their children's kindergartens and described them as friendly and helpful.

The principal in my child's kindergarten is very helpful. I mean she sometimes considers my opinion. If I tell her about a problem, she keeps searching for the reasons and tries to sort it out.

Mother of a child with an intellectual disability

However, three parents stated that the principals at their children's kindergartens were not sufficiently qualified to supervise special education institutions. These parents felt that principals at such institutions should have educational management qualifications as well as special education qualifications.

She [the principal] got a degree in special education, but I think it's not enough for leading an educational institution. She should at least have a postgraduate degree in educational management because she has many responsibilities, such as managing the teachers and communicating with the community.

Mother of a deaf child

7:3 Parental involvement

Since the literature in this field supports the argument that involving parents in the educational process is more likely to positively influence children's educational outcomes, parents in this study were asked whether or not they had participated in the education of their children. Their answers generally revealed a low level of involvement in their children's education and learning. While some parents spoke about activities that they had participated in, others tended to justify why they did not get involved.

7:3:1 Involvement activities

Generally, the parents interviewed regarded themselves as not actively involved in kindergarten events. They mentioned a relatively limited range of involvement

activities, both home-based and kindergarten-based. The activity with the highest participation rate was that of dropping their children off at school in the morning and picking them up in the afternoon. Some parents stated that this was the only involvement activity in which they could take part.

To be honest, I never participated in educating him. But every day I take him to the kindergarten and collect him in the afternoon.

Father of a child with an intellectual disability

Another involvement activity in which most parents participated was kindergarten meetings. Most parents reported that their children's kindergartens held monthly meetings that they normally attended; these meetings, which were somewhat formal, allowed them to obtain information about their children's progress.

Usually, his [the child's] mum goes to the kindergarten when they call us to attend the parents' meetings. She goes there and asks them some questions about our son.

Father of a deaf child

However, some parents noted that these meetings gave them limited time and did not always touch on topics they considered important, and that teachers could be overly reassuring about their children's progress and behaviour. For example, one parent said:

Every time I'm asking the teacher about her [my daughter], she [the teacher] keeps saying, 'Your daughter is a good child; your daughter is making good progress'.

Mother of a blind child

Some parents also reported that they had visited their children's kindergartens outside of meetings, but these visits were rare and were typically made when

children were experiencing problems. These reports may indicate that teachers did not regularly contact parents or provide them with relevant information about their children's progress.

If there is something urgent I go to the kindergarten. For example, my child came home crying once. I went to the kindergarten to ask the teacher what the reason was.

Mother of a blind child

Another involvement activity mentioned in parent interviews was that of helping children with their homework, which some parents perceived as supplementary teaching for their children at home.

They sometimes teach her letters or numbers and they write simple homework on her notebook; for example, colouring the letter A or the number 1. I keep pushing her to do that. You know if I didn't do so, she wouldn't learn.

Mother of a child with an intellectual disability

Although parents also recognised attending courses or special events in their children's kindergartens as an involvement activity, few of them actually participated in these activities. Such events included Mothers' Day celebrations, which only mothers (and not fathers) attended, and birthday parties arranged by the parents in their children's classrooms. Kindergartens also ran courses such as Braille reading and sign language for deaf and blind children; some mothers took part in these courses.

They conducted a free course for the parents to learn the Braille language. I attended that course; it lasted for five weeks.

Mother of a blind child

The last involvement activity that arose during parent interviews was that of teaching children positive behaviour, values, and personal characteristics. When parents talked about this activity, they described it as a familial or parental responsibility.

The family has a big role in educating the child, whether he is disabled or not. I think the kindergarten can't teach the child everything. My son, for example, was jumping and moving several times, I taught him to keep calm. I was taking him with me to the mosque. He learned respect for older people there.

Father of a deaf child

It was striking that none of the parents had been involved in decisions about their children's curricula or objectives. Usually, setting curricula for children with special needs requires parents' participation (Dinnebeil and Hale, 2003), but the interviews in this study suggested that such involvement did not take place.

I don't expect that any special education setting in Jordan allows or asks parents to do such a thing [take part in planning the curriculum], because they have their own curriculum, including the objectives, and you're not allowed to see this curriculum.

Father of a child with an intellectual disability

The interviews also revealed that mothers tended to participate in more involvement activities than fathers, which was probably the result of the disparate roles of fathers and mothers in Jordanian culture. Fathers are expected to handle the financial aspect of childcare, whereas mothers are expected to be the primary care providers; this includes handling school-related issues as well as domestic ones. The involvement of mothers and fathers alike was limited by certain barriers, which are discussed in the next section.

7:3:2 Barriers to parental involvement

Since the parents in this study generally reported low levels of participation in their disabled children's education, they were asked to describe the factors that had limited their involvement. The most frequently mentioned barrier to parental involvement was the absence of opportunities to participate in the educational process. Most parents reported that neither their children's classroom teachers nor their principals had requested their involvement in kindergarten activities.

They never asked me to take part in their activities. For example, they never asked me what skills I would like to learn; they never invited me into the classroom. If they asked me to do such a thing, I would be willing to get involved.

Mother of a child with an intellectual disability

This failure to encourage parents to engage in their children's learning could stem from many factors. Teachers in Jordan may not value parental involvement and/or may not be aware of the advantages of such practices, and some teachers may even perceive the presence of parents in the classroom as an intrusion.

Another factor hindering parents' involvement was an inadequate understanding of their disabled children's educational needs, which rendered them unable to develop the skills required to meet these needs. This was combined with a belief that educating children was the teachers' job and should therefore take place in kindergartens rather than in the home.

I don't have experience. I don't know how I can treat him. Sometimes he speaks with me using sign language; I can't understand him. I think teaching him is not my work; it's the teachers' job and they're supposed to do it.

Father of a deaf child

Some parents stated that their involvement was limited by a lack of free time. Commitments such as busy work schedules (particularly for families in which both parents were employed full-time), social obligations, and caring for other children reduced the extent to which parents could involve themselves in their disabled children's education.

To be honest, I can't find free time to visit the kindergarten. I'm a head of department and my husband is an engineer so we can't leave our work. The kindergarten runs a meeting for parents every month. I can't usually attend this meeting.

Mother of a child with an intellectual disability

The least-mentioned involvement barrier was the issue of kindergarten locations. Parents whose children attended a kindergarten far from home needed additional time and transport to take part in school activities and attend meetings.

They [the kindergarten] sometimes invite me to attend activities there, like the Mother's Day party. But I can't get to the kindergarten because I haven't got a car, and you know how difficult it is to get there.

Mother of a blind child

7:4 Kindergarten environments

The kindergarten environment should maximise developmental opportunities for disabled children in safe, healthy conditions, and should take into account the additional needs of disabled children and their parents. The location of the kindergarten, the design of the building, and classroom structures all contribute to creating this atmosphere.

7:4:1 Kindergarten locations

One of the main concerns raised by parents was the location of their children's kindergartens. The majority of parents argued that the kindergartens did not foster a safe and healthy environment. Most of the kindergartens were situated in crowded, primarily residential neighbourhoods, or on major roads, which placed disabled and/or vulnerable children at risk. For example, one parent stated:

Directly beside the kindergarten there is a police station. I mean, what types of people come in and out from the police station? Sometimes [they are] criminals and sometimes you can see the policemen beat somebody. And the kindergarten is on a main road filled with many big vehicles. I don't think this is a suitable place for kindergarten. You know there is a comprehensive medical centre by the other side of the kindergarten.

Father of a deaf child

Transportation issues were another major location-related problem. Although some kindergartens provided transport for their students, many parents interviewed found it inconvenient to bring their children to kindergarten in the morning and collect them in the afternoon every day, particularly if they lived far away from the kindergarten site. A few parents also claimed that their children's kindergartens were not well signposted.

It is so far from our home – 15 kilometres. The kindergarten bus doesn't reach our area so we have to send our child to the nearest point that the bus can reach. If they could provide more buses, it would be okay. But the location of the kindergarten is a problem. Many times we face problems when no one has time to send him to the kindergarten bus and pick him up. Sometimes I can't do it myself and his mother or his uncle can't either, so it is a problem.

Father of a deaf child

Unsurprisingly, parents who lived close to their children's kindergartens had no transportation-related problems in this respect; the kindergarten buses could easily collect their children, and in some of these cases, parents did not need to use any vehicular transportation to take their children to kindergarten.

For me, the location of the kindergarten is excellent. I'm lucky as I'm living close to this kindergarten. I don't have to pay for a bus or a taxi. It's only five minutes' walk.

Mother of a blind child

The availability of transportation services clearly affected parents' interactions with kindergartens, to the point where some parents' transport situations may have been the deciding factor in choosing kindergartens for their children.

7:4:2 Kindergarten buildings

The parents interviewed consistently stated that the kindergarten buildings did not meet the specific needs of young children with disabilities and therefore failed to offer educational opportunities in a real learning environment.

The building of the kindergarten is miserable. Clearly you can note that. It doesn't give you a sense of welcoming. I don't feel it's suitable for those kinds of children because there are stairs and fences.

Mother of a blind child

All of the kindergartens in this study were originally family houses that were renovated for young children with disabilities. However, they still suffered from an absence of communal facilities such as large outdoor play areas or indoor halls.

The kindergarten building is completely unsuitable. There is no playground or any place for children to play freely. I wish there was a playground filled with many toys because my daughter enjoys swinging

and playing with balls. But unfortunately the kindergarten has no entertainment area.

Mother of a child with an intellectual disability

7:4:3 Classrooms

All parents in this study expressed dissatisfaction with the structure of their children's kindergarten classrooms. Their criticisms focused on issues such as available space, ventilation, heating, decoration, equipment, and the number of students in the classroom. There was a consensus among the parents that kindergarten classrooms should be more spacious and that the current classrooms did not allow children to work freely on diverse activities throughout the room.

To be honest, the classroom is very small. It is probably not more than sixteen square metres and...has a small window. Don't forget how cold it is in the winter. There is insufficient heating which affects their ability to touch things.

Mother of a blind child

Some parents mentioned the teacher-child ratio, reporting that each classroom contained a large number of children but was managed by only a few teachers. Parents also stated that there were children with different types of disabilities in the same classroom; this was particularly prevalent among parents who had children in private kindergartens. They expressed concerns that teachers would not be able to pay adequate attention to each individual child as a result.

To be honest, it has very bad classrooms. Some of these classes are more like storage areas rather than classrooms for young children with learning disabilities, and they put 14 children in it. The problem is that they mix children with cerebral palsy, autism, and intellectual disabilities together. All those children are educated by only two teachers.

Mother of a child with an intellectual disability

Despite the majority of parents being dissatisfied with the kindergarten environment, however, they were marginally satisfied with having found educational institutions for their children, many parents employing the expression ‘something is better than nothing’ to describe their perceptions of the situation. This expression was more frequently used by parents whose children were enrolled in public kindergartens.

But, thank to Allah that there is a place where he can go. As I told you, it was so tiring before we knew about this kindergarten. It is somewhat good. I mean, something is better than nothing.

Father of a deaf child

These accounts suggest that parents perceived their children’s kindergartens as respite services which allowed them to take care of responsibilities beyond caring for their disabled children.

7:5 Outcomes experienced

The degrees to which disabled children improve in special education kindergartens are a clear indicator of these kindergartens’ efficacy. The parents in this study were therefore asked what outcomes they experienced from the services provided by their children’s kindergartens.

7:5:1 Outcomes for children

Most parents acknowledged that their children had shown improvement in functional sensory and motor skills, communication skills, academic skills, and social and behavioural skills. While the largest improvements in children’s development were described by parents of deaf children, the majority of parents in this study stated that their children had improved after spending time in a kindergarten setting.

Yes, he has been improving in different ways. His walking and running became better. He is better at expressing himself... In the past he kept shouting and crying. Now he can speak, although his speaking is not easily understandable. He can deal with other children in an acceptable way. Overall he is much better than before.

Mother of a child with an intellectual disability

Despite these favourable reports, some parents noted that their children had learned negative behaviours in kindergarten. From those parents' perspectives, this was the result of mixing children with different types of disabilities in the same classroom, as they tended to imitate each other's behaviours. Interestingly, all of the children in question were being educated in private kindergartens.

His behaviour became worse than before because the centre has different types of disabilities, so he sometimes came back home and started imitating the behaviour of other children – walking, talking, crying, etc. This was a problem that his mother and I were faced with.

Father of a child with an intellectual disability

Parents were also asked for their opinion on the length of the school day. The great majority of parents noted that school days at their children's kindergartens were approximately as long as those of ordinary kindergartens, and suggested that this scheduling fostered a sense of equality between their children and non-disabled children.

They take him at around 8:00 am and he comes back between 11:30 am and noon. I think this is good.... they can feel like they go to a normal school and see teachers and other children.

Father of a deaf child

No parents believed that school days at their children's kindergartens were too long; in fact, some parents argued that their children needed additional time at school to receive extra support.

She spends approximately four hours from Sunday to Thursday. To tell the truth, it's not enough time for a child with intellectual disabilities because she needs more time to achieve goals.

Mother of a child with an intellectual disability

7:5:2 Outcomes for parents

Although the overwhelming majority of parents felt that they were better off enrolling their children in special-education institutions, their responses regarding how they themselves were affected by these kindergartens were divided. Some parents stated that their children's kindergartens improved their knowledge of care and learning strategies:

I felt very nervous about bathing him. They showed me a very helpful and comfortable way to do so. They also taught me how to deal with toilet training issues.

Mother of a blind child

Other parents argued that their children's teachers lacked the ability or knowledge needed to enhance their parenting skills, and were unable to suggest ways of offsetting the effects of their children's disabilities. They further suggested that the teachers were not trained to work with parents of disabled children:

I don't think the teachers in the kindergarten can support the parents. You know this issue needs special skills. I don't think they have these skills.

Father of a deaf child

However, even these parents stated that their children showed signs of improvement compared to the period preceding their enrolment in kindergarten.

7:6 Discussion

Numerous studies suggest that the most desired outcomes from early intervention programmes are enhanced quality of family life and increased parental satisfaction with early intervention services (Carpenter, 1997; Bailey *et al.*, 1998; Bailey *et al.*, 2004a). This study indicated that these outcomes may not have been fully achieved.

Parents were relatively happy with the way that teachers treated them and their children. These attitudes may have resulted from the aftermath of struggling with negative social attitudes, particularly since the majority of participants had no basis on which to compare kindergarten services. Most parents noted that their children's kindergartens were the first special-needs or special-education service provider that they and their children encountered firsthand, and in many cases no alternative service providers were available to parents; this corresponds with McNaughton's (1994) argument that the satisfaction with special-needs services expressed by parents of disabled children often stems from a lack of experience with other services. In this study, parents' satisfaction with their children's kindergartens may also have resulted from low expectations regarding disabled children's services and facilities. This seems particularly true for the parents whose children were enrolled in public kindergartens; some of them perceived the services as highly acceptable, since they paid little to nothing in tuition fees (Koydemir-Özden and Tosun, 2010).

Parents frequently reported that their ideas were not valued and were not incorporated into their children's education. This may reflect teachers' perception of themselves as experts or providers of knowledge, and of parents as the beneficiaries of their knowledge – a relationship that parents are often forced to accept in order to

keep receiving services for their disabled children (Hess *et al.*, 2006). However, this relationship conflicts with Eleweke *et al.*'s view that: *"the success of early intervention is dependent to a large extent upon the development of relationships between professionals and family members in which family members assume an important role in assessment procedures and in the development and implementation of intervention programs"*. (2008, p.195)

According to this argument, the channels of communication between special-education kindergartens and parents require more two-way development, thus highlighting the need for such institutions to adopt a family-centred service delivery model wherein parents are seen as managers or decision makers, and service staff members provide supplemental guidance and assistance (Wilson, 2002).

The advantages of an effective relationship between parents of disabled children and service providers have already been widely discussed in previous studies (Dinnebeil and Hale, 2003; Paige-Smith and Rix, 2006). Summers *et al* (2005b, p.65) defined partnership as *"mutually supportive interactions between families and professionals, focused on meeting the needs of children and families, and characterized by a sense of competence, commitment, equality, positive communication, respect, and trust"*. (2005b, p. 65). The results of this study suggest that neither parents nor teachers were aware of these advantages.

Current approaches to parental education of disabled children concentrate on empowering parents and engaging them in decision-making (Hess *et al.*, 2006), and parents in previous studies showed high levels of involvement in their disabled children's education (Bailey *et al.*, 2004b; Jinnah and Walters, 2008; Laws and

Millward, 2001). However, most parents in this study were not involved in their children's education to this extent. Their involvement corresponded more with the study carried out by Miedel and Reynolds (1999), which found that the most frequent parental involvement activities were attending school meetings and taking their children to and from kindergarten.

The parents in this study felt that their relative lack of participation in their children's education was partially due to poor communication with teachers; in fact, they commonly reported that the main hindrance to their getting involved was not being asked to do so by teachers. This result largely corroborates the findings of Hess *et al* (2006), who found that families had a willingness to take part in educating their disabled child but had no established connections with teachers. Other reported barriers to involvement, such as a lack of knowledge and kindergarten locations, were also similar to those mentioned by participants in previous studies (Lamb-Parker *et al.*, 2001; Wehman and Gilkerson, 1999). Additionally, the absence of alternative service providers may have negatively affected parental involvement (Paige-Smith and Rix, 2006). On a larger scale, the absence of legislation in Jordan regarding parental involvement probably contributes to the lack of actual parent-teacher partnership in delivering early intervention services. This stands in contrast to countries such as England, which places greater emphasis on the engagement between parents and teachers in educating children with disabilities (Dale, 1996; DfES, 2004; Wilson, 2002) and grants parents the legal right to receive an annual report of their children's progress (Russell, 2003).

Another area in which parents expressed dissatisfaction was that of the kindergarten climate. Many parents in this study felt that their children's kindergartens did not provide healthy and safe environments for disabled students. As previous studies point out, the physical characteristics of schools can increase or reduce the ability of children to learn (Cohen, *et al.*, 2009; Ehrenberg *et al.*, 2001; Stewart, 2008). In addition, parents who lived far from their children's kindergartens had difficulties taking their children to and from kindergarten every day, which suggests that the availability of special-education kindergartens in Jordan needs improvement.

The issue of teacher retention also arose when some parents expressed their concern about the negative effect of frequent teacher rotation on their children's development. Retaining teachers is a major problem in the special education field (Billingsley, 2004; Dempsey *et al.*, 2009) due to factors such as burnout, poor school environments and a perceived lack of support from colleagues (Gersten *et al.*, 2001; Miller *et al.*, 1999). The parents interviewed in this study, however, viewed teachers' decisions to leave their jobs as financial ones, motivated by the pursuit of higher salaries outside of Jordan.

The benefits that parents receive from early intervention services are defined by Bailey *et al* (2008) as 'family outcomes'. These consist of five foundational outcomes for families: understanding their child's strengths, abilities, and special needs; knowing their rights and being able to advocate effectively for their children; helping their child develop and learn; having access to support systems; and having access to desired services, programmes, and activities in their community (p.195). Most parents in this study made it clear that these outcomes were not always being

achieved. Although the kindergarten teachers expressed empathy with the parents' situations, the parents felt that the teachers were not sufficiently qualified to understand and meet their needs, which may have indicated anxiety about the teachers' competencies.

7:7 Summary and conclusions

The majority of parents interviewed were somewhat happy with their communication and relationships with their children's kindergarten teachers, but reported that their suggestions were not considered in the practical learning process and, in some cases, mentioned that the teachers were not adequately trained to support parents of disabled children. Although all parents interviewed expressed satisfaction with their relationships with their children's kindergarten principals, very few parents commented on the principals' qualifications.

Parents generally had a low level of involvement in their disabled children's education and learning. Many parents described activities that allowed them a certain amount of participation in their children's education; however, they also mentioned a range of factors that limited the extent to which they could get involved.

Most parents considered the locations of their children's kindergartens to be inappropriate, as the buildings were often too far away and did not maintain a safe, secure learning environment for young disabled children. They also stated that classroom structures did not meet children's needs or encourage them to improve, and that high student-teacher ratios and placing children with different types of disabilities in the same classes created less than optimal learning environments.

Overall, parents felt that their children had been positively influenced by attending special-education kindergartens. However, parents with children in private kindergartens claimed that their children tended to imitate the negative behaviours of other disabled children.

Chapter 8: Parenting a disabled child in Jordan

8:1 Introduction

Parents of children with disabilities often experience more parenting challenges and stresses than parents of normally growing children. This chapter aims to examine the experiences of Jordanian parents raising a child with a disability (figure 7). The first section concerns parental reactions towards the original diagnosis of the disability including shock and denial, grief and anger, and acceptance. The reactions of other family members have also been highlighted by some parents.

Having a child with a disability has an inevitable influence on the way a family functions. The next section of the chapter discusses the impact of disability on the family. In particular, it examines the effect having a disabled child may have on marital stability. Discussion the strains that the family faced including marital stability, fears about the future, psychological stress, and social stigma.

Parents were asked about the support available for them, as revealed by their first-hand experiences. The resources of formal and informal support which they had accessed were discussed. A few parents were found to be reluctant to seek formal support and went on to clarify the reasons for their stance.

Undoubtedly, most Jordanian parents with a disabled child would be assisted greatly if they could gain access to additional resources or capacities that will help them meet the child's needs and allow the family to cope in the various domains of everyday life. The parents interviewed expressed their need for information, financial

assistance, and social and emotional support. Also, the need for certainty about their situation and a normal family life was highlighted by many parents.

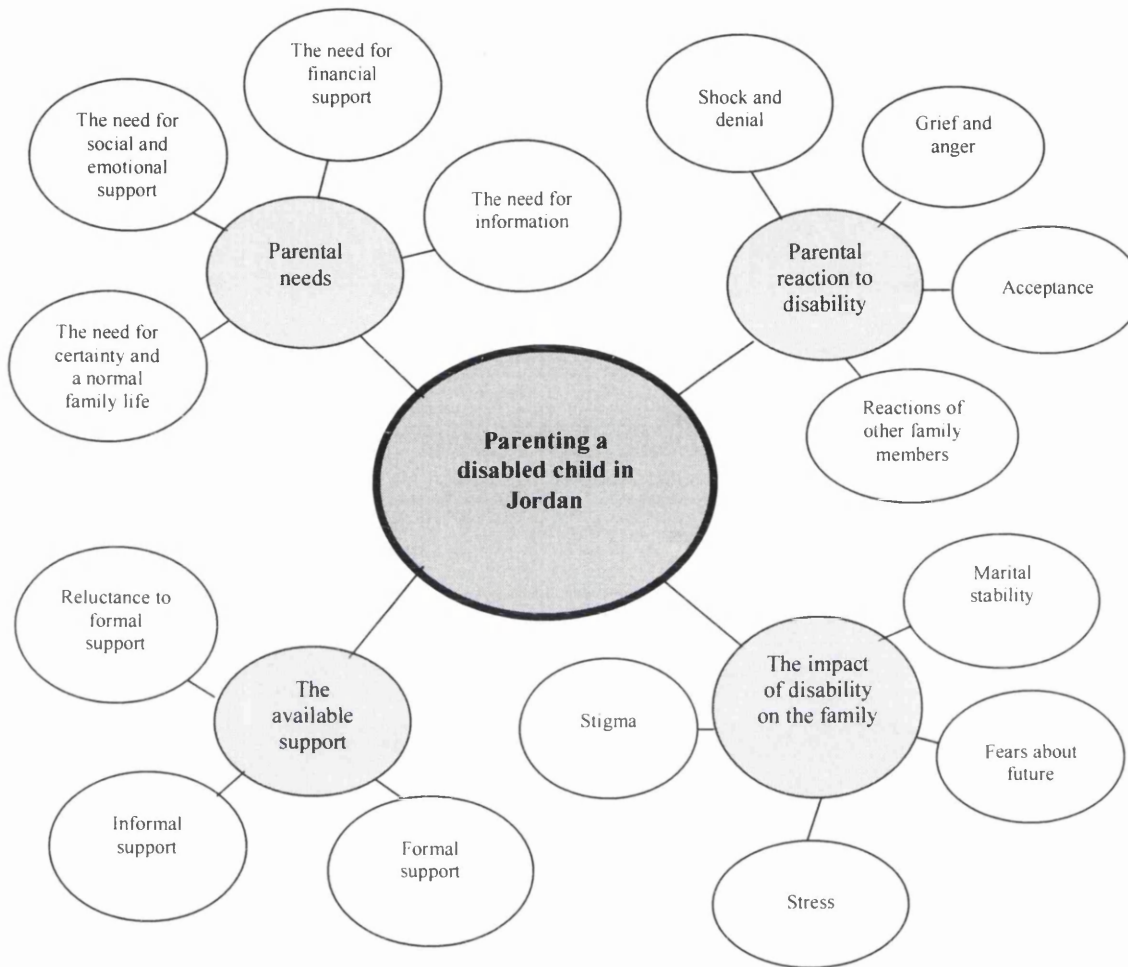


Figure (7): The main categories of response for the fourth emergent theme, ‘Parenting a disabled child’, including the four subthemes and related categories.

8:2 Parental reactions to disability

When parents learnt that their child was disabled, they usually displayed a range of reactions. Unsurprisingly, these reactions were usually highly negative, and could be

emotional or physical, or both experienced at the same time. Generally, some parents experienced a series of reactions (shock, denial, grief, anger, and acceptance), whereas others might discretely experience only one or more. Not all the parents necessarily went through all these reactions. There was no clear evidence of how long these reactions lasted. While some of the parents appeared to experience the full gamut of reactions in a few days, others seemed to take years to work through their emotions and arrive at a state of acceptance. Further, the intensity of parental reactions to disability varied between open devastation and an outward display of feelings under control. Generally though, these diverse reactions fitted into a process of adjustment to the disability, which might take more or less time, but typically culminated in a degree of acceptance.

8:2:1 Shock and denial

Shock and denial were often the initial reactions that the parents felt towards discovering their child's disability. Losing the perfect child that parents had dreamed of might lead them to express intense and highly emotional reactions when they heard the diagnosis their child's disability. Almost all the parents reported a feeling of shock when they had heard that their child was disabled. For most, the shock was accompanied by an initial denial of the disability; the parents refused to believe that the child they had longed for was in fact disabled.

It was my sixth attempt to get pregnant; I did six In vitro fertilisations (IVF). You can't imagine how we were happy to receive the baby after nine years of marriage. It was a real shock when the doctor told me. You know I told the doctor "impossible. My son is not disabled". It was a terrible shock.

Mother of a child with an intellectual disability

The response of shock to the diagnosis of disability could be understandable; this was because for most parents disability was a remote possibility that only happened to others. Many had built up optimistic expectations about the new baby during pregnancy, often constructing an idealised picture for their coming child and his or her future. For example, one parent reported how she has been thinking about what her son might study and which university he would attend. She reflected on how her hopes had collapsed after her son's disability was confirmed:

Wallh (I swear) I didn't expect that and I disbelieved what the doctor had said at the beginning. It was a terrifying shock. It was like... you know when you build up a very beautiful castle (like what we see in the carton films) and suddenly without any warning signs... the castle was blasted down. I was dreaming that Ramie would be a student in the Engineering School.

Mother of a child with an intellectual disability

During this phase of shock and denial some parents had socially isolated themselves and their children from their communities. They tended to avoid talking or meeting with anyone, they preferred being alone in their homes.

When the doctor said to me that my daughter wouldn't be able to see, I went home directly and switched off my mobile phone. We stayed for four weeks without calling or visiting anyone. When our relatives or neighbours asked us for a visit we were apologising to them.

Mother of a blind child

Further, some of the parents reported feeling devalued and incomplete as a result of the existence of their disabled child. In some cases this led parents to try for a period to hide their disabled child from people they knew. For example, a parent confessed that she did not let his neighbours know about or see his disabled daughter. She said:

When our neighbours were visiting us we were putting Haifa in a separate room or sending her to my mum's house. Our neighbours didn't know about Haifa's situation until she reached the age of three years old.

Mother of a child with an intellectual disability

From the interview data, and perhaps reflecting cultural attitudes in this part of the Middle-East, the language and tone of the parental stories was rather different for men and women. Mothers' accounts contained more open acknowledgments of shock, distress and denial than did those of the fathers. Interviews with the mothers contained stronger emotional reactions as well as more reflection on the impact of disability on subjective feelings and personal identity. Although something similar might be observed in any part of the world, Arabian culture places a heavy burden of explanation on the mothers in such situations. It is the mother rather than the father who is perceived as being responsible for carrying the child and managing the birth, and by implication – when the things go wrong - it is the mother who may face a degree of putative blame.

Even after the initial shock had subsided some parents continued to deny the existence of their child's disability. This was manifested in parents' reluctance to give up optimistic and unrealistic expectations of recovery which might lead them to keep moving between different doctors and the professionals (see section 5:3:2), to find someone who could tell the parents that their child was not disabled.

8:2:2 Grief and anger

Some parents felt grief following the diagnosis. They experienced sadness and sorrow as they had lost their dream of the perfect child. While some parents expressed temporary grief, it was chronic for others. Each time they noted the

developmental discrepancy between their disabled child and peers of the same age, the grief was triggered. In a variety of everyday situations when their child was expected to speak, walk, or play, their child's problem could trigger moments of deeply-felt grief.

You see the boy, he isn't like other children. He doesn't play like them. He has delay in walking. Here in our block there are four kids of his age. He was not developing like them. He was delayed in crawling and walking. When I bring toys for him, he doesn't pay attention on them. He doesn't play like other children. It's a painful situation. You don't know how very sad I was when the ordinary kindergarten didn't accept him.

Mother of a blind child

Many mothers in this study expressed feelings of grief through periodic crying. Some told about how they felt the weight of responsibility and duty for the child's future that now fell on them, especially in the light of the paucity of the available services for children with disabilities in their local communities. Crying was described by two mothers as the only thing they could do.

After I'd left the hospital I stayed two days crying. I didn't know what to do. Sometimes my husband tried to calm me down, but I couldn't do anything except cry.

Mother of a child with an intellectual disability

Feelings of anger were also reported by the parents when the disability had been diagnosed. Some parents felt angry at themselves as they had helped produce a disabled child. This was particularly true for the parents who looked back and concluded that they had carried on with unhealthy practices during pregnancy or committed a wrong in their previous life which was now attracting a punishment. Such respondents felt guilty and blamed themselves for the disability.

I was smoking during my pregnancy but I didn't smoke during the first three months of my pregnancy. Do you think this is the reason why Noor is disabled? I wish I hadn't smoked at all. I didn't expect smoking would affect my child to this extent.

Mother of a child with an intellectual disability

When I was 27 years old, my dad was suffering from Lung Cancer; he stayed in the hospital for long time. My entire family members were around him except me because I was working in Saudi Arabia, collecting money. My father wanted to see me but I didn't come. I chose the work at the expense of my dad. This was a very bad response from me. I should have come to see my father before he passed away. This event always follows me in my life.

Father of a child with an intellectual disability

Other parents turned their anger towards the people in their communities or the professionals. This may be because the professionals were unsympathetic and adequate services were not available. Also, the fact that the parents were powerless to remove the disability or change the situation, might make them feel angry.

There were some specialists who didn't treat us in a humanistic way. They were only thinking of exploiting their time. This is something miserable.

Father of a blind child

The type of disability was a notable factor that influenced the degree of grief amongst the participants. The parents of deaf children expressed the least feelings of sadness and sorrow compared with the other parents. This may be because of the positive attitudes toward the deaf children compared with the other disabled children, which most likely derives from the high degree of independence that the deaf children can achieve as well as the fact that deafness often does not affect the child's appearance.

8:2:3 Acceptance

When the parents realized that their negative feelings would not remove the disability or change the situation, they gradually accepted their child needs for special education. The process of adapting to the reality of life with the disabled child started from the time they tried to understand their child's disability, searching for the pertinent information and the available services; and thus finding an appropriate placement for their child. They also began to get to grips with the task of finding adequate resources and support for their child and themselves.

We've done many tests and we've seen many doctors as well. Unfortunately, nothing has been changed. The time was passing and she has become older, she's now turned three years old. One time her father told me "We should now concentrate on improving her skills and help her to discover the world around her".

Mother of a blind child

As parents move towards the stage of acceptance of the disability, they started to be more aware of their child's abilities, understanding his or her strengths and weaknesses. Most of the parents spoke about the skills that their child had. They started highlighting the positive aspects of their child's abilities. Some parents spoke of their enjoyment of celebrating their child's achievements. This might help to make disability more acceptable.

He has been awarded a prize as he had memorised a chapter of the Koran. And he read some verses from memory. I'm proud of this because I don't think normal children can do that at this age.

Mother of a blind child

The parents not only reported acceptance of their children's disabilities but also that they accepted their new situations. They started trying to manage their daily life

activities so as to cope with a disabled child. For example, a mother described how she had started to come to terms with the changed circumstances of her life. She said:

At the beginning (when Ramie was born), not all people around us knew about him. I wasn't accepting anyone to talk about Ramie or even talk to me. After a period of time, I started looking for anyone to talk about Rami's problem. I felt comforted when anyone talked to me about his case. I think somehow the situation is normal now. I take him with me to our social occasions.

Mother of a child with an intellectual disability

Although all the parents expressed a kind of acceptance of their child with disabilities, the negative emotions that were experienced in the previous phases never totally disappeared. From time to time the initial reactions might re-surface. The denial and grief re-emerged again especially when the disabled child failed to achieve a desirable goal or when the problems of education and training needs became manifest. Also, a few parents oscillated between periods of acceptance and moments when old hopes were rekindled as they sought out new health professionals, or even fortune tellers who hinted at the possibility of a better outcome.

Last year we heard that there is a seer in Ajloun city in the north of the country. Our neighbour advised me to book an appointment with him, he might help us, and he could cure children by natural herpes. We went into his home and he gave us a mixture to put it in our son's food. We followed his recommendation but unfortunately there was no positive result.

Father of a child with an intellectual disability

Many of those parents who seemed to adjust more quickly to their child's disability were people who emphasised their strong religious convictions. As mentioned earlier, most Jordanian people follow Islam. Muslims believe that events happen by Allah's will and therefore should be respected and accepted. One of the core

messages of Islam is that Allah may test his followers in different ways (e.g. wealth, illness, and offspring) and the reward depends on the difficulty of the test (see section 2:6). Frequently, many parents mentioned that their piety and reliance on Allah had facilitated and helped them to accept their disabled child.

Although it was a horrendous shock for me, thanks to Allah, we are true believers so we directly accepted him.

Mother of a blind child

Therefore, the disability was seen as a test from Allah; it was created to examine the faith of individual person in the family and his or her capacity to accept that fate with thankfulness and patience.

8:2:4 Reactions of other family members

Like most Jordanian parents, most respondents were living in an extended family where the family consisted of the biological parents, their children, grandparents, aunts, uncles, and other family members. Some parents highlighted the reactions of grandparents to diagnosis of the disability. Grandparents of disabled children almost always experienced similar stages to those affecting the parents (shock, denial, grief, anger, and acceptance). While some grandparents expressed greater grief than the parents, they too generally came round to accepting their disabled grandchild.

I mean when my mum knew about my child's problem, she was shocked. You know she told my husband "this is not true, I think there is something wrong in his diagnosis". Also my father in law was disappointed and depressed.

Mother of a child with an intellectual disability

In Jordanian culture, there is a proverb saying that “the grandchild is more lovable than his or her parent”, which means that the grandparents tend to love their grandchild more than they love their son (father of grandchild) or daughter (mother of grandchild). They may expect to renew themselves through their grandchild and often experience a feeling of fulfilment of their family name being preserved for posterity. But unfortunately such expectations are shattered by the discovery of their grandchild’s disability. Accordingly, the grandparents in this study experienced highly negative emotions initially. However, most grandparents appeared to move quickly to accept their disabled grandchild, especially as they might not be responsible for his or her constant care. Typically they only had to deal with their grandchildren part-time.

My father enjoys playing with Noor. He comes to our home every Friday asking about Noor, and he sometimes tells me that he is missing Noor. He loves him so much.

Mother of a child with an intellectual disability

8:3 The impact of disability on the family

Caring for a child with a disability almost always creates tremendous challenges within the family system, and the parents in this study experienced lasting dilemmas while they were raising their disabled child. This section examines the strains that have been identified amongst the participants including: marital stability, fears for the future, psychological stress, and stigma.

8:3:1 Marital stability

From the parents' accounts of their experience of raising a disabled child, the relationship between husbands and their wives was very often affected by the child's disability. Many mothers felt themselves to be vulnerable as giving birth to a disabled child cast doubt on their ability to produce a healthy child. This might lead the husband to take an additional wife in three families (out of 53) or to divorce his first wife (as happened in two families). For example, one mother stated:

When Ruba was born her father told me "I need to be a father of a healthy child". It wasn't my fault entirely, but he didn't understand that. The problem was his (the husband) parents, they persuaded him to marry another women. He did that and I stayed alone.

Mother of a blind child

In this study divorce and polygamy occurred only among the less educated parents, and this may account for the coping strategy used by those fathers. Limited education resulted in a poorer understanding of the scientific basis of disability and may have been associated with greater reliance on traditional cultural explanations such as the culpability of the mother.

Some of the parents reported that the child's disability created conflicts within the family. One of the main sources of the conflicts was making decisions about the disabled child when parents disagreed about the best way forward. For example, sometimes the conflict occurred when one parent disagreed with the other about how to manage the child's behaviour in the home. Some mothers tended to be overprotective while the fathers were more likely to voice pragmatic concerns about making progress, which led to conflict between them.

When Belal wants to go upstairs to his uncle's apartment, I don't let him to go alone because you know there are steps, so I go with him. My husband always argues with me, saying that Belal should go alone and I shouldn't go with him. My husband believes that Belal can do many things. For me I think so, but not climbing the stairs alone - he can't do that. You know, Belal is still too young... To be honest my heart doesn't let me leave him to go alone because I fear that he may fall down.

Mother of a blind child

Conflicts arose not only found between father and mother but also between the siblings and spouses, or between the siblings themselves. Not all siblings were comfortable with the new roles and expectations placed on them by the arrival of the disabled child, and some actively rebelled or refused to comply. This might cause conflict within the family. For example a mother said:

Sometimes his brother refuses to help him when they're at home or to play with him. For example, last week I was busy in the kitchen and I couldn't leave, I was cooking. I asked his older brother to bring him from the kindergarten but he refused. So I had to reason with him in order to convince him to bring his brother.

Mother of a blind child

Furthermore, as there was no financial benefit offered by the government for most parents who were caring for a disabled child, the parents (and particularly the fathers) had to work overtime to get extra money, which in turn caused a problem for the parents in finding time to spend together. For example a mother described how the disabled child affected her relationship with her husband. She said:

You know we don't have time to see each other; we stopped having our meals together. He (the husband) increased his working hours. So every day he comes home late at night. There is no time to sit down together or even to talk. Before Hussam was born, we used to spend at least four hours together daily for enjoyment.

Mother of a child with an intellectual disability

By contrast, some positive consequences of the presence of a disabled child were found. Many parents emphasised that their disabled child brought them closer together, sharing the responsibilities and having open communication about matter concerning their disabled child.

We've become closer to each other, sharing our anxieties, responsibilities. My husband keeps encouraging me when he sees me that I'm tired, and I do the same when I see him despair. I can say that she (the disabled child) enhanced our family cohesion.

Mother of a deaf child

It was notable that most disabled children in this study were the youngest child in their families. It has been argued that Jordanian parents pay insufficient attention to birth spacing intervals, partly because fertility is given a high social status (Market Research Organization, 2007), and there may be a suspicion that giving birth to a disabled child had affected the family size. The birth order of the disabled children might indicate that when the parents become aware of the responsibilities arising from giving birth to a disabled child, they decided not to have more children. Additionally, in some cases this could be combined with the unknown reasons of the unexpected disability, and parents' fears that subsequent children might also be disabled.

8:3:2 Fears about the future

Most of the parents were clearly worried about what the future would hold for their disabled child; they frequently mentioned the lack of competent and reliable services around after they are gone. This concern was reported insistently by parents of children with an intellectual disability, whereas parents of deaf children and parents

of blind children were more concerned about finishing formal education and the vocational opportunities that might then be available. Probably, as children with an intellectual disability were less likely to attain meaningful independence, their parents were concerned about basic care rather than higher education and finding paid work.

I don't know if I die what the future will be for her. What's going to happen when me or her father are no longer around. Who will pay her fees? Here, the provision for people with intellectual disability doesn't help at all. I hope I could ensure a good quality of life for her before I'll be gone. You know no one can stay alive forever.

Mother of a child with an intellectual disability

The parents' fears for the future might be derived from the unreliable and unpredictable system of provision and the limited chances to ensure access to high quality services for children with disabilities in the future. Also, parental awareness of the negative attitudes encountered by many towards disabled people increased the fears of the parents. For example, a parent said:

I'm not worried about him now because he goes to the kindergarten. He is dealing with young children like himself and with the teachers... But I don't know if he will be able to find a real friend when he gets older; a friend who won't belittle him or laugh at him when he talks for example.

Mother of a deaf child

The absence of available information about the disability might have left the parents unrealistic and worried about their disabled child's future. For example, two mothers of children with Down's syndrome had fears of losing their disabled children during their adolescence. Further, the lack of parents' knowledge about the nature of the conditions involved made them unsure about how they could deal with their disabled children and how they could meet their needs in the future.

I'm wondering how I can answer her questions in the future if she asks me about her disability. I'm sure she will ask me one day about many things like what does the sea look like? As she gets older her questions will increase.

Mother of a blind child

8:3:3 Stress

One of the main consequences of the children's disabilities expressed by their parents was psychological stress. They described the continuous burden of responsibility for their child welfare including acting as caregiver, financial support, and physical helper. Parents whose children were intellectually disabled appeared to talk in more detail about the burdens of caring for their child. While deaf children and blind children are more likely to perform adequately in the activities of daily life (e.g. toileting, dressing, and personal hygiene), children with intellectual disabilities do less well. Further, men and women expressed stress in different ways, using different language, and giving examples from different areas of their lives.

When women respondents talked in interviews, they often used more overtly emotional language and spoke in greater depth about their feelings. This is probably in line with prevailing cultural expectation in Jordan.

In the morning I need to wake him (the disabled child) up, help him to wash, put on his clothes, feed him, and take him out to waiting for the kindergarten's bus. At the same time I have to deal properly with the other tasks like washing, cleaning up, cooking for the lunch, and caring for other children. It's really exhausting.

Mother of a child with an intellectual disability

Usually, the fathers acted as a breadwinner while the mothers were used to spending more time providing care and taking more of the burden. Nevertheless, in addition to

the constant burden, the parents mentioned a variety of stress factors: worries about the child's future; other people's perceptions of the child; stigma; maladaptive behaviour by the child; feelings of embarrassment; sibling jealousy; and parental conflict. For example, a parent said:

I reached this position (head of a department) and my wife is a teacher. So far we don't own a house, all our money is spent on our kids...So it's financially exhausting. From the social side, people don't understand what disability means...So our society doesn't understand the disability issue, so I find myself suffering...In addition, my wife keeps blaming me, she wants me to be responsible for everything, she doesn't want to take on any of the responsibilities, she tells me that "I'm employed full time like you"...The most difficult thing I face is inside my own home, I can't feel comfortable, I can't take my rest at all because my son is hyperactive and he has extra emotions. Sometimes I need time to study or work on my research, but he never lets me do so.

Father of a child with an intellectual disability

The numerous stresses which parents of children with disability had encountered affected their certainty about their situation and their sense of normality (see section 8:5:4); it placed them many times in the position of being abnormal parents of an abnormal child.

8:3:4 Stigma

Parents presented a variety of examples regarding their feelings of stigma. In the interviews, some parents tended to explain the stigma by how the public treated them and their children as being different. Public perceptions that they were needy parents who should receive pity and support reinforced parents' awareness of stigma. There is a strand of Jordanian cultural belief that suggests that having a disabled child is a source of disgrace. The poor access to educational services and support for children with disabilities was also presented by the parents as evidence of stigma. Parents

reported that their children were rejected and excluded from enrolling in the public kindergartens because they were labelled as disabled. From the interview' accounts, stigma was an ever-present preoccupation of almost all. Indeed all the respondents recounted examples illustrating negative social attitudes toward children with disabilities and their families. Many parents felt that their disabled child was unwanted and unaccepted by the others in their communities; they were seen as different, aggressive and unstable.

For a long time I hadn't visit a neighbour of mine, but about two months ago I decided to visit her because I wanted my son to play with her kids. When I had got into her house, she saw my son wearing a black lens in his glasses. She asked me "what is the problem with your son" I told her... Then she sent her kids out and kept saying to my son "be careful, don't touch anything, don't move, sit down please"... I'd say I don't know what people think about a blind child.

Mother of a blind child

The societal response towards children with disability affected the parents' ability to adjust; it prevented them from engaging and pursuing the normal activities of daily life. For example, many parents reported that they avoided taking their disabled child when they went shopping, going to public places, or visiting other people. They were aware that this would bring them under the gaze of other people. The parents felt themselves under observation and at risk of receiving pitying comments or reactions. Some experienced feelings of being blamed, as if they had committed a sin in a past life for which the disability was a punishment. For example, a parent said:

Sometimes people make me feel poor or bereaved, and other people looking at me as if I have done something bad or wrong in my previous life and Allah punished me by giving me a disabled child.

Father of a child with an intellectual disability

Unfortunately, in most areas of Jordan, disability has been deemed to be something shameful. This notion has created a real barrier for many parents to be involved in social occasions and entertainment events. The coping mechanisms that parents developed to shield themselves from negative attitudes, might lead to social isolation and feelings of disengagement from the local community.

Further, not only the parents felt that they were stigmatized by having a child with disability, but also that the stigma extended to other family members. Many parents said that their non-disabled daughters might end up unmarried; in their view the sister of a disabled child was less desirable as a partner to men in her community. This was often due to the belief that the production of a healthy child depended mainly on the woman and all types of disabilities could be inherited. Also, a sense of embarrassment had been experienced by siblings of the disabled child when they were dealing with their peers.

My oldest daughter finished her first degree last year and she got a good job at a famous company. I mean she is well educated, has a good salary, and most importantly she is pretty. So she's got everything that the young men are looking for these days to marry a girl, but no one has tried to ask us about her. You know why? Because she's got an intellectually-disabled brother.

Mother of a child with an intellectual disability

It is worth mentioning that the nature of child's disability might affect the degree of social stigma encountered. Hearing impairment appeared to be a less stigmatizing condition when compared with visual impairment and intellectual disability. This was notable since the parents of deaf children made fewer references to negative social attitudes toward their children in their communities.

8:4 The available support

Like many other parents of children with disabilities, Jordanian parents have sought support for themselves and their disabled children. The parents were asked to provide details about the formal and informal support which they had received and who they perceived as providing valuable assistance and help. Although limited formal support was available for the parents, they regarded help and support from the formal institutions they encountered as very important. This section discussed the different types of support parents had received from such institutions, and other types of support received from informal sources.

8:4:1 Formal support

As mentioned earlier, the parents pointed out four public bodies with responsibility for disability services. They were: the MoH, the MoSD, the MoE, and the HCAPD. By investigating the services that the parents received from these authorities, several forms of support can be identified. All parents of deaf children spoke about hearing aids as a service provided by the MoH or the HCAPD. Also, batteries for these aids were received.

The only type of support we've got was the hearing aids from the HCAPD. To be fair, I've got batteries as well, but it was for one time only.

Father of deaf child

Another type of support highlighted by some parents was financial assistance. This type of support was received from the HCAPD and the MoSD. A group of parents whose children were in a private educational setting reported that their children's

tuition fees had been partially paid by the HCAPD. Also, four families were receiving a simple monthly salary as a kind of financial benefit from the MoSD, but they expressed concern that this financial support was not enough, and they worried that these benefits might be reduced or stopped.

With regard to the HCAPD, as it is the umbrella organisation for all people with special needs, I got support from it... I applied for financial support, after one month I went there then I was told that I'd been accepted. They would pay 60% of my son's tuition fees.

Father of a child with an intellectual disability

Four parents of blind children, in particular, considered that Braille tools were a type of support their children received from the HCAPD.

I went to the HCAPD asking for support. They told me "we don't support blind children, but we can help you when your child learns to use the Braille system. At that time come back and we may provide a Braille machine for your child". They did that after my son had learnt the Braille language.

Father of a blind child

The HCAPD was supporting children with physical disability by offering aids in order to facilitate their walking or mobility. Two parents of the participants received a wheelchair for their disabled children after they had proved that their children's conditions required such equipment.

I applied for a wheelchair in the HCAPD, because my daughter has problems with her legs. Thank to Allah they helped me with that. Although they delayed, finally they provided it for her.

Mother of a child with an intellectual disability

It is worthwhile mentioning that ten parents in particular received support from an official body, but this body was not directly responsible for supporting children with

disabilities and their parents. This support was provided by the Royal Hashemite Court. From the parents' perspective the Royal Court has supported them by giving them exemption from paying the medical care costs for their children's treatment.

The doctor said to me "your son needs an operation on his retinas". My financial situation did not allow me to pay for this operation, so I went to the Royal Court appealing to them. They helped me; they gave me an exemption from payment – for what the operation cost in the Royal Medical Care City.

Father of a blind child

8:4:2 Informal support

Most children (42 out of 53) in this study were living in a traditional extended family with both parents present, as well as other family members. This provided the opportunity for the parents to put in place a variety of informal support arrangements involving family members, friends, relatives, and neighbours. The parents regarded the informal support they received from these sources as essential for managing their daily life activities. For most of the parents, emotional support was found to be the most commonly mentioned type of support they received from the family members. Talking about the disabled child; accepting the disabled child; understanding the parents' feelings; and encouraging the parents to be optimistic were mentioned as areas in which the wider family could offer emotional support.

My mum keeps asking me about Saber and discussing his progress with me. She always motivates me and my husband, pushing us up. Also, my mother in law does the same. Sometimes, when I feel sad they understand that and they try to simplify things for me. I think our life without them seems to be so hard.

Mother of a child with an intellectual disability

Spending time with the disabled child was another type of informal support recognised by the parents. Grandparents were the main source of providing this kind of support; they sometimes offered a respite for the parents by taking the disabled child to their home overnight, and at other times they came to the child's home to offer care there.

Sometimes when we are invited to a party for example, we can't take her (the disabled child) with us. Because you know the parties usually last for a long time. So my parents take her to their home. We can go without worrying about her, because they love her and they can adequately deal with her.

Father of a child with an intellectual disability

A few parents regarded receiving information and gifts from the neighbours and the relatives as examples of informal support. The parents valued the informal support offered by the people outside the family.

We've got a respected neighbour, he is very kind. When he hears anything to do with blindness, he immediately informs us. Also, he gives many toys to our child on different occasions.

Father of a blind child

The type of informal support reported only rarely by the parents was financial assistance. Very few parents received money from the child's uncles, aunts, grandfathers, and grandmothers as a way of supporting them. When provided such support was sometimes used to pay for the child's tuition fees or buy essential equipment.

My brother is wealthy. He told me "if you need anything for Morad, just let me know". Last month his hearing aids became weak. I told him "Morad needs new hearing aids"; he directly bought good quality hearing aids for him.

Father of a deaf child

From the interviews, the parents tended to perceive any kind of involvement by others (emotional, physical, or financial) in their disabled child's care as a source of informal support. Sharing the parents' responsibilities toward the disabled child might make the parents feel that their child was not rejected by the wider society, which in itself was a kind of support.

8:4:3 Reluctance to seek formal support

One surprising finding was that certain parents avoided turning to the public authorities to obtain formal support. When questioned at interview as to why they did not wish to benefit from the support offered by the public bodies, parents volunteered three main reasons. Negative societal attitudes were the most common reason mentioned which discouraged the parents from seeking formal support. The parents reported that they expected negative reactions from the public authorities and also the local community, so they had not tried to access formal support.

Honestly, I never searched for support from the governmental institutions. I can't stomach how the employees think there. If I went there, they would think that I'm begging for my child. And some people around here may think the same. They may think I'm happy with my child's disability because that makes me eligible for financial support from the government.

Father of a deaf child

A very few parents reported that being wealthy was a reason behind their unwillingness to search for formal support. This was connected with the belief that the formal support should be targeted on poor families who had a disabled child.

I never went to the MoSD, because I thought that the MoSD existed to help needy people. Needy people have the right of support rather than me. My circumstances were better than hundreds of parents of disabled

*children... My situation is better than many parents of disabled children,
I am wealthy.*

Father of a child with an intellectual disability

In addition to being wealthy and the negative attitudes, the bad reputation of the services provided by the public sector was perceived as a barrier for a few parents seeking formal support.

I didn't want to search for formal support because of my impressions regarding the MoSD's kindergartens. The children there got no attention and got no training. They only spend time there; it's like a shelter.

Mother of a child with an intellectual disability

8:5 Parental needs

It has been said that behind each child with special needs there is a parent with special needs. This might reflect the range of additional needs that become manifest to the parent of a disabled child. This section investigates the nature of parental needs and what respondents believe is needed to meet them. The need for information was at the forefront for the parents. Also, emotional, social, and financial support was demanded by respondents. Moreover, parents perceived that meeting these needs would reduce uncertainty and help them sustain a self-image as normal parents of a normal child

8:5:1 The need for information

All parents in this study had an overwhelming desire for information; the types of information desired varied over the time and between parents. The respondents emphasised their needs for information from the first time that their child's problem was suspected and throughout the diagnostic process. They wanted to know

everything about their child's disability: what had caused it; the treatment available; future expectations; and how to deal with their child day to day. They also wanted full knowledge of what services were available for their child in their local community (see sections 5:2:2 and 6:4:1).

When I heard that my daughter was blind, a flood of questions came into my mind. I wish the doctors or the professionals could answer my questions or at least gave me leaflets about how to improve our child's communication skills.

Mother of a blind child

The information needed may have helped the parents to come to terms with diagnosing the disability and reduced their anxiety, which in turn would facilitate making the right decisions for their disabled child. However, the parents indicated that their need for information was unmet. As the parents did not receive sufficient information from the professionals, many of them reported carrying out independent searches for information using the internet.

I tried to find formal or informal institutions that would give me information about my child's case, but I didn't find any, so I got access to the internet in my home. Now I can keep updated about my child's development... I hope there is a Jordanian site providing us with information about everything regarding our disabled child.

Mother of a child with an intellectual disability

Also, receiving information from the kindergarten's staff about dealing with the child was perceived as very important; the parents wanted to know how they could manage their child's disability. This might have given them an opportunity to collaborate with the teachers in educating their son or daughter.

I'm wondering if the kindergarten could send me information about how they teach him (the disabled child); I would carry on their work and make his improvement faster.

Mother of a blind child

Giving parents information about their disabled child may motivate them to be engaged in their child's treatment and education (Pain, 1999), and in turn consolidate the relationship between the parents and the professionals. This means that the sharing of information between parents and professionals may reflect a positive connection between them.

8:5:2 The need for financial support

Caring for a child with additional needs places a financial cost on the family. Thus, it was expected that the parents would express their need for financial assistance. Parents frequently mentioned the financial burden caused by the various extras needed to bring up their disabled children. Some parents spoke about their need for money to pay for medical services, such as treatments, medicines, doctor checks, and sometimes operations. This can be connected to high cost of the medical care services for disabled children that was discussed earlier (see section 5:4:2).

We urgently need financial help. Each time we go to the doctor to check his eyes I pay 15 JD. And don't forget the cost of the drops which are prescribed by the doctor. It may be decided that an operation is needed for him later, I don't know how we could manage that.

Mother of a blind child

Affording special equipment for the disabled child was also a pressure on parents' finances. As mentioned elsewhere in this study, the nature of disability might have required medical and educational devices, for example, hearing aids and batteries for

the deaf children; classes and Braille tools for the blind children; and some children with an intellectual disability needed wheelchairs. Further, the high cost of the special education services (e.g. specialized therapists) placed an extra financial burden on the parents.

Honestly, he (the disabled child) left a financial crisis on our shoulders. I wish we could have found support. You know how everything is expensive these days. You know the cost of special education centres. I'm thinking of hiring a professional to improve his language, but unfortunately I can't. We don't have enough money to do so.

Mother of a child with an intellectual disability

The lack of public support as well as the lack of the available services which were offered by the public sector may illustrate the necessity of financial support for the parents. This was more important for the parents whose household income was low. However, to meet the financial requirements for children with disabilities, some parents tended to extend their working hours or have an extra job.

8:5:3 The need for social and emotional support

Although the parents in this study had received informal support from family members, relatives, neighbours, and friends, they constantly expressed their needs for social and emotional support. The parents were looking outside the circle of their close friends and families to find support; they were keen to share their experiences with others and they were willing to listen to the others' experiences. Also, they emphasised their need for formal networks to support them emotionally and socially including doctors, psychologists, social workers, and teachers.

Most of the time, I'm looking for someone to talk to. Someone who could understand my feeling and respect my child's situation. I hope there is an

association for parents of children with intellectual disabilities, so we could meet and talk about our children. We can learn from each other's experiences.

Mother of a child with an intellectual disability

Unfortunately, a parent to parent support programme has not been established in Jordan yet. However, for some parents social support was found to be more beneficial than other types of support. The parents felt supported and strengthened by their families and friends; this was buffering them from the burden of caring for their disabled children, and ameliorating the effect of the disability.

8:5:4 The need for certainty and normal family life

The constant desire of the parents for information and support was more likely to reflect their needs for certainty and normal family life. The parents expressed their need to be confident about their child's situation and what the future would hold for them; they also expressed their need for certainty about being good parents for their children. Thus, giving the parents pertinent information may empower them to control and construct the new conditions that they had found themselves in by diagnosing the disability.

I mean the information may help us in coping with our situations; I need to know what the expectations for my child are. What I would say is that neither me nor his dad knows what we should do with him in different situations. And what is the right thing to do? Even I don't know what I could tell my relatives about his case.

Mother of a child with an intellectual disability

The parents were trying to regain a sense of normality through managing their new situation. While some parents underwent various changes in their life, others tried to

ignore their anxieties and worries in order to see their lives as normal. For example, a mother tried to forget the symptoms of her child's disability. She said:

Sometimes I told myself "forget that, he will learn to walk like normal children, he has got too much time and he is still young".

Mother of a child with an intellectual disability

The need for normality and certainty was more urgent for the parents during the period of diagnosing the disability since they felt themselves as being out of control.

When they told me he was going to be blind I had no idea what would happen to him. I didn't know if he would stay alive or if he was going to die.

Mother of a blind child

One illustration of this search for normality was the extraordinary effort some parents made by moving around to consult a variety of professional experts in the quest for an acceptable diagnosis. The parents were looking for cures or/ and answers for the stream of questions they had, to reduce their uncertainty or to transfer them from being parents of an abnormal child to parents of a normal child. However, although many parents had developed a type of adaption to their disabled child, their feeling of uncertainty would never completely disappear.

8:6 Discussion

For most Jordanian parents, receiving an unexpected diagnosis of a disability in their children led to a kind of mourning process since this diagnosis led to the loss of their dream of their child and destabilized their view of themselves as ideal parents of an ideal child (Green, 2003); their plans for being good parents for a perfect child were then no longer viable. The parents were not prepared for such a diagnosis, even when

the diagnosis came gradually. They went through phases of emotion, usually starting from a feeling of shock and ending with acceptance of the disability. These reactions were recognised by some researchers (Garske and Turpin, 1998; Graungaard and Skov, 2006; Huang *et al.*, 2010; Rogers, 2007) as a process of adaptation to and coping with disability. Although the parents in this study tended to react in an emotionally and physically negative way to the diagnosis of their child's disability, the intensity of the negative responses tended to reduce gradually in the years following the diagnosis (Heiman, 2002; Rogers, 2007). Thus, the results of the current study support previous research which indicated that parents whose child is diagnosed with a disability or chronic illness often experience a series of reactions such as shock, denial, anger, sorrow, fear, uncertainty, blaming the medical professionals, and acceptance (Heiman, 2002; Huang *et al.*, 2010; Russ *et al.*, 2004).

The parents expressed their reactions in different ways depending on their perception and understanding of their child's disability. The concept of disability varies across cultures and is influenced by different factors such as: type and severity of disability; attitudes of the family; availability of financial assistance; legislation concerning disability; access to the physical environment, and societal acceptance (Ravindran and Myers, 2011). Parents' reactions to a disability might also be influenced by their religion, for example, the belief that disability is a gift from God (Jegatheesan *et al.*, 2010) or a test of the religious faith of parents (Raman *et al.*, 2010; Hadidi, 1998) was evident in this study. Having a child with a disability was seen by some parents as an opportunity to prove their strong belief in Allah and to acknowledge and accept their fate. Seeing the disability from this scope was reported in some Arabian neighbouring countries, such as the UAE (Crabtree, 2007) and in Kuwait (Raman,

2010). Ravindran and Myers (2011, p.4) suggested that *“parents who embrace a fatalistic view of their child’s disability (e.g., God’s will) are more likely to accept their child’s condition as fate or destiny and have lower expectations of cure or improvements from any treatments used”*. Studies conducted with Muslim populations found similar perspectives on disability. For example, in Pakistan, children with Down’s syndrome were seen as a blessing from Allah (Bryant *et al.*, 2011). This ideology was often combined with the notion of being a good parent and practicing self-sacrifice to meet the needs of the disabled child. Skinner *et al* (1999) in a qualitative study investigated Latino mothers of children with disabilities, and found that most of the participants represented themselves as good and sacrificial mothers.

The findings suggested that Jordanian parents of children with disabilities were confronted with great challenges such as parental conflict, fears for the future, high levels of stress, and perceptions of being stigmatised. The present results support past suggestions that there are high levels of stress, depression, and care giving burden in parents of children with disabilities (Brett, 2004; Heiman, 2002; Mobarak *et al.*, 2000; Oelofsen and Richardson, 2006; Roberts and Lawton, 2001). Disabled children can remove the sense of equilibrium in families’ lives (Fitzpatrick *et al.*, 2007). This notion emerged throughout this study from the accounts of the parents interviewed; they experienced a unique set of stressors compared with families of children without disabilities. Different stressors were identified throughout Jordanian parents’ journey with disability, which were found to be triggered by a number of factors: obtaining a clear diagnosis; attempts to access support; finding appropriate treatment and intervention services; coping with the financial burden; and disrupted family and

social relationships. Green (2003, p.1367) stated that *“the act of caring for a child with a disability is undeniably time consuming and can have a dramatic impact on the daily lives of whole families”*. Jordanian parents in this study gave numerous examples of the daily inconveniences and pressures that they experienced over time; they felt psychologically and physically exhausted.

Parents harboured deep fears for the future; their main future concern was what would happen to their child when they were no longer around. A pervasive statement reported by most parents was: “Who will look after our child when we have gone”. Perhaps the limited nature of the available services and society’s perception of disability in Jordan contributed to the development of such fears. Green (2003) found that her respondents experienced future worries as an outcome of their feeling of stigma. In the UK, McGill *et al* (2006) surveyed parents whose children attended 52-week residential schools for learning disabilities. They found that 75 percent of their respondents expressed extreme concerns about their child’s future care and support needs. Although there are differences in the support systems available and the age of children in McGill *et al*’s study, the parents of the current study voiced similar worries about the future.

Analysis of the interviews suggested that parents varied markedly in their perceptions of what challenges they would face. Their experiences were influenced by a complex interplay of the child, the parents, and the culture. The type of children’s disability influenced parents’ perception of their challenging situations. Among the group of parents whose children had an intellectual problem, the burden of bringing up the child was emphasised more compared with other disabilities.

Previous studies have contended that an intellectual disability is likely to impose greater pressures on parents than other kinds of disability. For example, some studies have found that having an intellectually disabled child could lead to increased parental stress (Baker *et al.*, 2002; Emerson and Llewellyn, 2008; Weiss, 2002). This can be interpreted to mean that children with intellectual disability demonstrated greater levels of behavioural problems than other children with disabilities (Baker *et al.*, 2002), which ultimately affects social skills development of the child and demands intensive care in their homes. In addition to the child's characteristics, parental characteristics could impact on the perception of the challenges that the parents faced. For example, in this study mothers many of the most vivid and heartfelt accounts of the burden of caring came from mothers rather than fathers. This result would agree with the existing (mostly quantitative) research which found that mothers of children with disabilities generally report greater strain than fathers (Emerson and Llewellyn, 2008; Herring *et al.*, 2006; Pelchat *et al.*, 2003; Raman *et al.*, 2010). Mothers of children with special needs are often more in charge of meeting the child's needs and they are most closely involved with interventions and treatment, while father's responsibilities lie mainly outside the home (Carpenter, 2000; Green, 2003; Sen and Yurtsever, 2007; Pelchat *et al.*, 2003; Raman *et al.*, 2010). This notion fits the Jordan case well, given that the mothers are the primary carers for their disabled children and the widespread belief that producing a healthy child depends more on the mother than the father. Also, complex explanations about the child and the causes of disability were more frequently demanded of the mothers than the fathers when they encountered the public.

Cultural beliefs and the availability of support systems where the parents live may also influence the effect of disability on the parents. In this context the perception and the attitudes of the community towards disability play a large part in the burden that is experienced by parents (Green, 2003). Participants interviewed indicated that some people in Jordan perceived the disability as a curse, a punishment from God for bad deeds, or the work of evil spirits (Croot *et al.*, 2008). This belief made the child's disability a source of embarrassment for the parents which led some of them to hide their disabled children and become isolated and stigmatised.

Consistent with previous research (Crabtree, 2007; Crawford and Simonoff, 2003; Green 2003; Kearney and Griffin, 2001), all parents interviewed perceived themselves to be stigmatised by their child's disability. This was notable throughout their stories about public reactions to their disabled children. Also, other family members experienced feelings of stigma. The parents provided examples about how their non-disabled sons and daughters encountered negative attitudes from people in their local communities.

The extension of stigma from the disabled child to his or her family and close relatives was discussed by Goffman (1963) as "courtesy stigma". Goffman's concept of stigma refers to an attribute attaching to individuals that is so deeply discrediting that it has the potential to spoil identity, and will typically lead affected individuals to manage social relations in a way that as far as possible limits the damage that this will entail. Courtesy stigma refers to being stigmatised as a result of the association with a person who suffers stigma because of some primary attribute. It leaves those affected, such as the parents considered here, in a deeply ambiguous position. Parents

are normal in that they perform ordinary social roles, but different because of their proximity to the stigmatised child. This means that in Goffman's (1963: 14) terms they are not automatically discredited, but rather discreditable. Because their own stigma arises from their affiliation with another rather than from an intrinsic characteristic, parents will often be able to manage situations – and the flow of information – so that they pass as normal (Birenbaum, 1970). Researchers have applied notion of courtesy stigma to the parents of children with intellectual disabilities or attention disorders (Birenbaum, 1970; 1992; Norvilitis *et al.*, 2002), and also to relatives of people with psychiatric illnesses (Byrne, 2000; Angermeyer *et al.*, 2003; Corrigan *et al.*, 2006). Angermeyer and associates describe the wide-ranging and highly-consequential nature of courtesy stigma in the four domains of interpersonal interaction, structural discrimination, public images of the condition involved, and access to social roles.

Courtesy stigma can also spread from the disabled child to others with whom they have regular contact. Professionals, such as teachers in special education, risk experiencing stigma because they work closely with children with disabilities (see section 3.9). One may theorise that some professionals counter this by emphasising the instrumental, expert dimension of their roles, and limiting social contact or personal relationships with the parents of their disabled pupils, which indeed appeared to be a common pattern in the settings studied.

One interesting extension of the courtesy stigma concept noted in the Jordanian context was that it was not merely that stigmatised parents themselves avoided contact with those outside their immediate social circle, but that professionals

assumed they would behave in this way. As my early research fieldnotes on negotiating access show, professionals acting as gatekeepers appeared to project courtesy stigma onto the parents and told me that parents would not want to discuss their experiences with a researcher. I will discuss the implications of this further in the next chapter.

It seems likely that negative attitudes towards disabled people in Jordan are generated by the lack of public awareness about the disability issue, the marginalisation or inattention to children with disabilities by the public authorities, and the negative images of disability provided by the media. These factors also could be considered as obvious manifestations of social stigma.

Siblings of children with disabilities in this study generally experienced similar challenges and feelings to those mentioned above affecting their parents. According to respondents, the disabled child's brothers and sisters had been impacted either directly or indirectly because of disability in the family. For example, they might be involved in caring activities and/or perceived embarrassment and stigma from their local communities. Research in this area has identified different negative effects such as conflict in the relationships between the siblings and between the children and their parents (Sharpe and Rossiter, 2002); an increased burden of responsibility at an early age (Stoneman, 2005); and fear and sadness (Hutton and Caron, 2005). These findings suggest a need to adopt a family-centred approach when planning and implementing services for children with disabilities in Jordan.

The study also suggests that children with disabilities and their families are oppressed and discriminated against. This provides an overall framework for how the

public look at and interpret the reality of a disability which paradoxically (given its negative aspects) fits well with the core assumptions of the medical model of disability. Thus disability is assumed to be a personal tragedy (Scullion, 2010), and the disabled child is seen as a failure or someone who does not belong in normal social settings since he or she cannot adapt to the environment (Brett, 2002). Accordingly, disabled children are seen as being of low priority (Dowling and Dolan, 2001); seen as a problem, focusing only on what they cannot do as a result of their disability; and devalued by their local communities. On this basis it can be argued that it is not only caring for a disabled child in Jordan which creates a burden on his/her family, but also the negative social stereotypes that parents must deal with. There is no culture of disability rights, and an absence of institutions promoting progressive disability policies. Dowling and Dolan (2001, p.22) suggest that "*the child does not handicap the family—society does*".

Respondents reported little in the way of positive effects from raising a disabled child in Jordan. Many researchers have examined the benefits of the existence of a child with a disability within the family, for example Boström *et al* (2010), Green (2007), Heiman (2002), Kearney and Griffin (2001), and Taunt and Hasting (2002). Generally, the parents interviewed in these studies were in agreement that they enjoyed child achievement and experienced a sense of family integration resulting from having their disabled child. Only a few respondents of the current study reported similar feelings. However, it must be borne in mind that, where a different support system is provided for children with special needs and their parents, more positive experiences were reported, for example, in the USA and the UK (Taunt and

Hasting, 2002), in Australia (Kearney and Griffin, 2001), and in Sweden (Boström *et al.*, 2010).

In the light of the constant burden that parents face in terms of caring for a child with a disability, the availability and accessibility of support may influence the management of the parents' situation. In Jordan, the available support that the parents discussed can be classified within two categories: formal and informal support. Generally, the parents perceived that the formal support available was deficient in terms of its scope and efficiency, though they found it helpful in providing some necessary services. The formal support included equipment, but insufficient financial assistance. The extended family, friends, relatives, and neighbours offered different types of support to the parents which helped them in reducing their feelings of isolation and made a difference in their lives. These findings add support to a growing body of research documenting the importance of both formal and informal support for the families in their adaptation to disability (Rogers, 2007; Russ *et al.*, 2004). Like some participants in Brett's (2004) study, some parents did not wish to benefit from the formal support provided by mainstream organisations.

From parents' accounts there was a need for improved intervention services which might ultimately enable them to manage their difficulties, enhance their capabilities to cope, ease tensions within the family, and provide better access to services. The need for information was the highest priority for the parents, primarily during the diagnostic process. Financial needs were emphasised by the parents to meet their financial obligations particularly the medical expenditure. Social and emotional

support from social networks was also desired by the parents. Finally, the parents were looking for certainty about their situation and some semblance of a normal life. These results are in line with the findings of the earlier studies, for example Bailey and Simeonsson (1988), Fisher (2001), and Hartley *et al* (2005). Also, this study confirms findings by Avis and Reardon (2008), Fisher (2001), and Russell (2003) who report an insufficiency of services and support for meeting the needs of parents of disabled children.

8:7 Summary and conclusions

When Jordanian parents of children with disabilities first discovered their child's disability, they almost always passed through a series of staged reactions, starting from 'shock and denial', then moving to 'grief and anger' and ending with the process of acceptance. Religious beliefs, the type of disability, and the gender of the parent might affect the intensity of parental reactions to the disability. Other members of the family, particularly the grandparents, were found to react towards the disability in a similar way to the parents.

While the existence of the disabled child affected negatively the spousal relationship for some families, a few parents reported that their disabled child had brought husband and wife closer together. Different strains affected the lives of parents of disabled children such as fears for the future; constant stress; and social stigma. These difficulties often varied from family to family because of differences in the available information and support, as well as the type of disability.

Limited formal support was available from the public authorities. While some parents talked about receiving special equipment for their disabled child, very few of

them were receiving monetary assistance. Also the parents spoke about informal support received from their extended families, neighbours, and friends. Surprisingly, a few parents spoke of their unwillingness to seek support from the public authorities.

The needs of Jordanian parents of children with disabilities were discussed. The main need for the parents was found to be pertinent information. As the children grew older and additional needs became manifest, many parents found themselves facing financial difficulties with limited prospects of assistance. The parents also expressed their need for social and emotional support since their child's disability made them feel isolated. There was a continuing preoccupation with finding some certainty regarding the family's situation and a desire to be normal parents of a normal child.

Chapter 9: Conclusions and recommendations

9:1 Introduction

This chapter summarises the main findings of the study and discusses parents' recommendations for improving the provision of services for children with disabilities in Jordan. Implications for practice are outlined and recommendations for future research are presented.

9:2 Summary of key findings

This study sought to investigate pre-school provision for children with disabilities and the experience of being a parent of a disabled child in Jordan. To achieve these aims, a qualitative design was employed using interview techniques. 64 parents of children with disabilities took part in 53 semi-structured interviews, which were carried out in two phases of data collection. After a thematic analysis of the data, four overarching themes emerged. These overlapping themes reflect the complexity of caring for young disabled children and receiving services in Jordan.

9:2:1 Parents' experiences of health care services

Parents' stories reveal unsatisfactory connections with health care providers, beginning from the initial suspicions of developmental problems and during and after the diagnostic process. Several problematic aspects of the treatment that parents received from health care practitioners were highlighted during the interviews. These included the following:

- Inappropriate methods of disclosing disability

- A lack of pertinent information
- Negligence on the part of hospital staff
- Negative attitudes
- Extended or overly long diagnostic processes
- Lack of understanding and updated knowledge
- Repeated referrals and a lack of coordination between services
- Downplaying children's problems
- Failure to track children's development
- The cost of health services
- Lack of special treatment for disabled children.

As a result of these deficits in the health care system, parents continued to feel uncertain and angry, continually moved between specialists for their children's treatment, experienced difficulties with accepting their children's disabilities, and were unable to generate realistic expectations for their children's futures. Moreover, parents' narrations about their experiences of health care services suggest that health care providers – and sometimes parents – view disability according to the medical model.

9:2:2 Access to services and support

After their children's disabilities were diagnosed, parents sought educational assessment and diagnosis. For some parents, educational diagnosis was a prerequisite for accessing support and educational services in their local communities. Other parents perceived educational diagnosis as a means of understanding their children's

conditions further and helping them to remove misconceptions about their children's problems. Generally, parents were dissatisfied with such diagnoses but were at least somewhat satisfied when professionals considered their opinions in the processes of assessing their children's abilities. Parents reported serious problems regarding the accessibility and availability of support and services, particularly those offered by the public sector. These problems included negative experiences with public employees, lack of coordination between authorities, shortages of human and financial resources, a dearth of information about available services, insufficient services, unequal service provision, and high costs. In particular, parents of deaf children experienced difficulties in obtaining hearing aids.

Parents' experiences of accessing available services and support further highlight the frequency with which disability is viewed according to a medical model. These findings call for a family-centred delivery of services.

9:2:3 Kindergartens for children with disabilities

Parents appeared to be relatively satisfied with educational provision in the kindergartens where their disabled children were enrolled. However, they noted problems in areas such as classroom teachers ignoring their opinions, staff qualifications and retention, kindergartens' inability to maintain safe and healthy environments, and difficulty getting to and from their children's kindergartens.

Parents' accounts reflect a limited amount of involvement in their children's education. The most common involvement activity reported by parents was that of transporting their children to and from kindergarten. The barrier to involvement most

frequently reported by parents was a failure on the part of teachers to offer them sufficient involvement opportunities. Parents experienced limited improvement in their children's development and received little support from kindergartens. This lack of effective partnership between parents and service providers underscores the need to adopt a family-centred model of service delivery.

9:2:4 Parenting disabled children in Jordan

When their children's disabilities were first identified, parents experienced reactions such as shock, denial, grief, anger, and acceptance. Disability affected their families in various ways by, for example, destabilising family relationships, creating fear and stress, and fostering stigmatisation. Although parents found both formal and informal support useful, they reported deficiencies in the support provided by public authorities. The existence of disability within Jordanian families created unique needs for information, financial support, social and emotional support, certainty and the ability to live normal lives. Parents stated many times that current provision for children with disabilities did not meet their needs.

Analysis of the data revealed that parental responses to the disclosure of disability were significantly influenced by complex interacting factors such as parental gender, the type and nature of the disability, the availability and accessibility of support, and cultural beliefs.

9:3 The limits of courtesy stigma

Courtesy stigma (Goffman, 1963) is a complex phenomenon with multiple dimensions. Not only do parents find themselves stigmatised because of their

relationship with their children, but there is the additional dimension that the professionals project this stigma onto parents and assume that it will shape parental behaviour. Indeed professionals see themselves also affected by courtesy stigma, and in some case may believe that if they engage with parents they will be stigmatised by their association with them. This appears to lead some professionals to emphasise the instrumental, expert aspect of their roles and remain socially distant from parents.

To a considerable extent, the assumption that professionals made that parents did not want to speak about their disabled child was inaccurate. Birenbaum (1970) points to the situational variability of courtesy stigma. He describes the three parental responses of: first, denial and evasion; second, acceptance of the stigmatised status; and third, what he characterises as a more ‘balanced’ position where parents show that they can function in the worlds of both the stigmatised and the normal. The professionals do not appear to have recognised this complexity or have anticipated the particular response that the researcher found with most parents in the study. The field notes taken during and after the interview indicated that most parents talked about the experience of disability surprisingly freely, going into considerable detail and in some cases being open about their feelings. Many indeed seemed to positively welcome the opportunity to talk about issues that they could not discuss with anybody else. Research in other domains has suggested that in-depth interviews can have a therapeutic effect for respondents (Aldridge and Stevenson, 2001; Morecroft *et al.*, 2004; Lowes and Gill, 2006), and it may be that a similar effect seen here was more powerful than fears of possible stigmatisation. Thus, it could be argued that

courtesy stigma is a more complicated phenomenon than the professionals in this study believed.

9:4 Recommendations for the improvement of services

This section presents recommendations based on parents' ideas about what needs to change with regard to a wide range of service providers and policy-makers. I have collated and listed the main recommendations about which there was a reasonable degree of consensus. When parents were asked about their recommendations for improving services, they tended to elaborate on their suggestions and seemed happy about being asked such questions. This highlights the parents' desire to be listened to and to develop effective frameworks for the provision of services for their children. The recommendations made by parents in this study fall into three categories.

9:4:1 Health care services

Children with disabilities usually have a greater need for health care services than non-disabled children. As a result, the parents of disabled children deal with a wide range of health care professionals (Avis and Reardson, 2008). In this study, parents offered various suggestions for the improvement of health care services for disabled children. Most parents stated that the communication skills of health care practitioners required improvement, and some suggested that training courses in how to deal with the parents of disabled children could help to accomplish this. For example, one father said:

The professional who delivered the news of disability should be trained to do such a thing. He or he/she should be sensitive about the parents'

feelings, being empathic. I guess such news shouldn't be provided all at once. I think it's better if doctors or nurses inform the parents gradually.

Father of a child with an intellectual disability

Other parents concentrated on increasing professionals' awareness of disability issues in order to enhancing their abilities to provide pertinent information and suitable advice to parents.

I advise people who work in hospitals, I mean the specialists of any department related to children's development, to do reading about the disability issues. They should know what the health needs for disabled children are, and explain clearly to the parents how to meet these needs. For example, if a child needs a test, doctors should detail how and where the test can be done. They are supposed to be trained to deal with parents of children with disabilities so they will not treat parents rudely.

Mother of a blind child

Parents also stated that health professionals should provide opportunities for them to take active roles during the diagnostic process. They recommended that doctors and nurses discuss with them all decisions relating to their disabled children's situations.

All my life, I've heard that health workers are angels. So they should give the mothers room to express their feelings and concerns about their children. They should ask us whether we want to do any test or not.

Mother of a child with an intellectual disability

Parents highlighted concerns about the continuous provision of free and inclusive medical insurance, recommending that health care professionals should make more effort to check the development of all newborn babies before they leave hospital and that an appropriate system should be established to ensure that children remain healthy after hospitalisation. These suggestions were made with regard to the MoH, as it is the main public institution responsible for treating, funding and supervising health needs.

... Please don't forget something very important, which is the insurance of health care. Disabled children should be medically insured from the cradle to the grave and this insurance should cover all health requirements, including any operations and medicines needed. I also hope they can offer free hearing aids and batteries regularly because children's ears become bigger over the years, so they need bigger sizes.

Father of a deaf child

The abovementioned recommendations reveal that parents desire family-centred services for their disabled children and support the argument that communication with professionals, particularly during the initial disclosure of disability, has a lasting influence on parents' abilities to cope with their situations (Dent and Carey, 2006; Fallowfield and Jenkins, 2004; Kerr and McIntosh, 1998). These recommendations also suggest the need for health care practitioners to develop effective protocols for communicating with parents, primarily in the early stages of disclosing disability, or to use published guidelines as suggested by researchers (Baird *et al.*, 2000; Buckman and Kason, 1992; Choi *et al.*, 2011; and Kisler and McConachie, 2010).

9:4:2 Educational systems for children with disabilities

Parents were divided in their perceptions of inclusive education, wherein children with disabilities are educated alongside their non-disabled peers (Garner, 2009). Some parents felt that their children had a right to inclusive education.

I think children with disabilities (regardless of the type of disability) should be educated in the normal schools. It is their right like other children. Why do I need to travel a long distance to get to my child's kindergarten? There is a kindergarten here, ten minutes walking distance. I hope one day this will happen in our schools.

Parents of a blind child

Parents also suggested that inclusive schools could increase their capacity to educate disabled children by ensuring the presence of trained teachers who specialised in special education, appropriate equipment and tools, and safe environments. Some parents, particularly those with high levels of education, tended to describe their ideal schools. For example, one parent stated:

Teaching all children, regardless of their characteristics, in the same school is a very good idea as it has many benefits for disabled children and their parents. But in that case, the school should have specialists in special education in addition to the normal teachers. Also, sign language translators should be recruited by the school as well as psychological counsellors. There should be a spacious ground for children to play and many educational aids and toys available.

Mother of a deaf child

However, implementing full inclusive education in Jordan would be dependent on a variety of policies and actions (Jones, 2004; Wilson, 2002), and would probably be a challenging, prolonged process. Attitudinal barriers would also need to be overcome, since, as this study shows, negative attitudes towards disabled children are still prevalent in Jordan.

Parents who advocated a separate special school system were afraid to enrol their disabled children in mainstream education. This was likely because they were aware of the effects of negative social attitudes on their children. Their suggestions revolved around establishing special schools for specific disabilities, which would ideally be equipped with tools to help disabled children to reach their full potential.

Normal children and their parents don't understand and accept children with disabilities. So I think they won't agree about mixing their children with our children in the same classroom or school. May be normal children insult our children in the school? I don't need to tell you how disabled students are treated by other students. You know, my

colleague's son has a limp and he is studying in a regular school. Students there keep offending him. What I want to say is that I suggest building an appropriate school for each type of disability and the government should provide a suitable curriculum for each disability, and staff these schools with qualified professionals

Father of a child with an intellectual disability

The above quotation places further emphasis on considering the attitudes of non-disabled peers if and when inclusive educational systems are implemented in Jordan.

Many researchers report that negative attitudes on the part of non-disabled students can be detrimental to interactions between disabled and non-disabled children in inclusive education (Laws and Kelly, 2005; Guralnick, 2006; Piercy *et al.*, 2002). Although the trend of educating children with disabilities in mainstream settings is spreading across the world, several studies indicate that parents are dissatisfied with this form of education (Park and Turnbull, 2001; Parsons *et al.*, 2009; Whitaker, 2007).

Regardless of their views on inclusive education, all parents in this study stated that access to services should be made easier. Their proposals for accomplishing this included the establishment of an official website listing available facilities and their addresses, and free transportation for children. Parents also suggested that one institution should issue all required documents to eliminate the need for travelling from one authority to another.

Why don't they issue the assessment report from the same educational facility? Why do I need to travel to Jable Alhusen to bring a report from there? And it is possible that when a father gets the CEDD he finds himself forgetting some documents. What should he do in this case? You know why this could happen? Because there is no obvious procedure that published by the government concerning how to access special education services.

Father of a child with an intellectual disability

To overcome the problem of teacher retention, special education teachers could receive special privileges such as increased salaries and reduced duties. Parents' suggestions regarding the educational system may reflect their struggles to access services (Chapter Six) and their problematic interactions with kindergarten teachers and staff (Chapter Seven).

9:4:3 Support for parents

Parents stated that families of children with disabilities require financial, social and emotional support. With regard to financial support, parents insisted that the Jordanian government could secure benefits for all children with disabilities by setting up policies to help parents to cover the additional costs of disability.

I imagine that the government can enact a law that explicitly pays money for our children. This is from the first time that children are identified as disabled. They should get us exemption from all taxes and offer carers for us if we want to go out for social activities or if we want to travel for a few days, for example.

Mother of a child with an intellectual disability

This statement and others like it call for Jordanian policy-makers to establish financial support allowances for disabled children and their carers, similar to the UK's Disability Living Allowance, Carers Allowance, and Social Fund (Preston, 2005).

With regard to social and emotional support, parents advocated the establishment of formal institutions to provide such support. Parents felt that support groups could

alleviate their feelings of isolation and allow them to share information with other parents.

I suggest organising support groups for parents of children with disabilities. It is very useful to find and talk to other parents who are in the same situation, and those parents can easily understand what you are saying. Also, when you know other parents, you feel that you aren't alone in this world.

Father of a blind child

Parents also recommended that school staff provide them with regular updates on their children and involve them in the learning process. This would allow them to develop strategies for coping with their situations, build realistic expectations about their children's development, and play active and valued roles in their children's education.

I recommend that people who are working in kindergartens keep informing us about everything related to our children and identify tasks for us to do, and they should be courteous and welcoming so we can understand our children and feel better.

Mother of a child with an intellectual disability

Following these suggestions would establish an equal relationship between practitioners and parents.

However, these suggestions may have been a way for parents to validate their opinions on current service provision for children with disabilities. For example, during the interviews, parents mentioned different costs and expenses in combination with a lack of financial assistance. By the end of the interviews, they placed more emphasis on financial support. This iteration could therefore confirm their accounts.

9:5 Key recommendations for policy and practice

This thesis has revealed significant weaknesses in the organisation of services for disabled children in Jordan, and it seems clear that fundamental changes will be needed if services are to be brought to the required standard. Against this background, this thesis proposes a number of general, system-wide reforms designed to improve the framework of care. More detailed facility-specific recommendations will only have value when this new organisational framework beds in.

- Meeting the needs of children with disabilities and their parents requires collaboration among the involved ministries and agencies (public, private, and voluntary). These institutions will be able to support disabled children and their parents more effectively if they work within a partnership framework. The creation of an integrated framework should aid collaboration and cooperative working, and result in clear care pathways for children and clearer information about care entitlements for parents. An overseeing body, probably within a lead ministry, will need to define the respective responsibilities of the different agencies and to assess their performance. This should be done by establishing formal accountability requirements, perhaps similar to those introduced by the 'No Child Left Behind' (NSLB) legislative plan (Bush, 2001) and the associated NCLB Act of 2001 in the United States (though with a less mechanistic testing regime).
- The above change should be supported by a change of focus from needs to rights. New legislation is needed to mandate comprehensive support for the rights of disabled children and their parents, and ensure proper

implementation of these policies. The new legislation could again adopt a similar approach to that utilised in the American NCLB Act.

- Educational reform should be based on research evidence and measureable results rather than professional opinions. In this context, the main three elements included in the American NCLB reform plan (Bush, 2001) should be taken into account when planning Jordanian reform: measuring how children perform in the school, offering assistance and motivation for the weak schools, and offering a choice of schools to parents.
- There is an urgent need to increase the numbers of experienced and trained specialists working with children with disabilities and their parents. Accordingly, Jordanian colleges and universities that train special education teachers should use a family-centred framework so that new teachers in the field will be equipped to deliver services effectively. Similar training can also be given to those teachers already working in the field.
- Enhancing the quality and the character of special education institutions is an important issue to consider, and where possible additional resources should be allocated to support this. There is a need to improve physical environments and also to provide schools with additional staff such as classroom assistants, teaching assistants or learning support assistants. Where possible, steps should be taken to motivate teachers by providing increased professional opportunities.
- Changing attitudes towards disability in Jordan is crucial, but could be difficult since these attitudes are formed by many interacting cultural and environmental factors. However, increasing public awareness of disability

issues, support from public authorities for disabled children, and better provision of information about disability via the media could help to create more positive perceptions of disability.

- Establishing associations or forums for parents of children with disabilities would allow for the discussion of relevant issues and the exchange of ideas with other parents. As shown in the research interviews, parents are willing to share their experiences with others. Policy-makers and parents could also hold regular meetings to facilitate parents' participation in negotiating changes and developing services. Such meetings would allow parents to express their opinions and views on the services they use, which could in turn encourage service planners and providers to improve provision and increase parental satisfaction (Summers *et al.*, 2005a).

9:6 Areas for future research

As in most studies, this research highlights important areas to be investigated by future research, as follows:

As this research focuses only on parents of young disabled children, collecting data concerning parents of older children with disabilities will allow for comparison between the services received by the two groups and indicate whether their circumstances differ.

The results of this study can be used to construct a validated survey instrument to investigate the quality of the services offered to parents of children with disabilities and other factors affecting their lives. Future quantitative research can examine the

topics of this study in a larger population of Jordanian parents based on such a survey.

A longitudinal study following parents as their disabled children grow up is highly recommended for an increased understanding of parents' situations.

As this study examined services delivered to young disabled children from the perspectives of parents, future research could explore the perspectives of the professionals who deliver these services.

A number of further in-depth studies could concentrate on the categories that emerged from this study's data and could involve parents of children with other types of disabilities, such as physical impairment, which could not be included in this study.

Since disability can impact all family members, there is a need for deeper investigation of the experiences of family members who are not parents, such as siblings and grandparents.

9:7 Conclusion

In conclusion, this research has set out to ensure that the voices of Jordanian parents of young children with disabilities are heard by exploring their experiences of caring for their children and receiving services. Findings revealed that parents were generally dissatisfied with the health care, education and support provided to them and their young disabled children. The quality of these services, along with cultural

attitudes toward disability, contributed to the challenges that parents encountered in caring for their disabled children and coping with their own circumstances.

The results of this study will hopefully improve the provision of services for young children with disabilities and their parents by encouraging policy-makers and stakeholders to devote more attention to enhancing current practices, which may in turn enhance parents' and disabled children's quality of life.

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Appendix (I): Information sheet for parents

Jordanian parents of young children with disabilities: Their experiences of care and receiving services

You are being voluntarily invited to take part in a research study. This is being carried out by a researcher from Swansea University and sponsored by Al-balqa' Applied University. Before you decide to take part, it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

What are the aims of the study?

The purpose of this study is to investigate the situation of pre-school provision for children with disabilities and the experience of being a parent of a disabled child in Jordan. This will involve a recorded interview with you if you agree to participate. The interview will be recorded and transcribed to ensure an accurate record of the discussion for analysis. I believe that the findings of the study would help in the development of policies and practices in terms of the services for young disabled children and their parents in Jordan.

What is the interview topic?

The interview topic will be related to your experience of the services and support that you and your child with special needs have received. Starting from the first time you were informed that your child had a special need. By the end of the interview, you will be asked to provide your suggestions to improve the services provision in Jordan.

Do you have to take part in this research?

No, you do not have to participate in this research. It is up to you to decide. You can sign the attached consent form and return it to your child's kindergarten to confirm that you want to take part, and if so, to arrange a convenient time and place for interview. Signing the consent form is to show that you understand what is involved in the study and you have agreed to take part. All research materials are confidential and can only be accessed by the researcher.

Please remember that you are free to withdraw at any time and without giving a reason.

What will happen to you if you take part?

If you agree to take part, I will ask you to take part in recorded interview with me which will be held at your own home or in our child's kindergarten or any convenient place and at a time that is convenient for you. It depends on your preference. During the interview any family member can accompany you.

What are the possible disadvantages and risks of taking part?

I am aware that some questions might touch upon sensitive issues for you during the interview. If you do not want to answer certain questions, that is fine. You can skip any question you do not wish to answer. You can finish the interview at any time you wish. Every care will be taken to ensure that you are comfortable with the content of the interview.

What will happen to the results of the study?

The anonymised data will be used to produce a research report. Associated publications will be presented in peer reviewed journals, and may be disseminated at conferences, as well as seminars and workshops with relevant professionals and policy-makers. You will not be identified in any related report or publication and pseudonymous names will be used when needed.

What should I do if I want further information?

Please feel free to ask me if there is anything that is not clear or if you would like more information about. My contact details: Mizyed Hyassat. Telephone: [REDACTED] E-mail 470516@swansea.ac.uk

Take time to decide whether or not you wish to take part.

Thank you for considering taking part and for taking the time to read this information sheet.

Appendix (II): Parent consent form

Dear parent,

This study is to explore the experiences of Jordanian parents of young children with disabilities regarding the services provision available for their young disabled children and their perspectives of caring for a disabled child in Jordan. You will be interviewed for about one to one and half hours to answer questions about what you think about the services which you and your child receive from early intervention programs. For example, your opinion about communication with professionals involved in educating your child, the timing and your satisfaction with the services, so we can highlight evidence to policy makers and a wider audience considering your view to develop early intervention services that are delivered for special needs children of an early age. The interviews will be done in one session, and they may be held in kindergarten or in your home if you prefer.

If you are happy to participate in the interview, please sign your name below and remember that you have the right to change your mind at any time during the interview, so you will be able to refuse to answer certain questions or even withdraw from the interview. You will not be identified by your name or by any other means in this research.

Please don't hesitate to ask for more explanation.

Regards

Mizyed Hyassat
PhD student
Centre for Child Research
Swansea University
E-mail 470516@swansea.ac.uk

I consent/ I do not consent to take part in this research.

Your name:

Date:

Signature:

Appendix (III): Short demographic questionnaire for parents

| Before the interview starts, kindly answer these short questions | |
|--|--------------------------------|
| What would you prefer me to call you during the interview? | |
| What is your relation to the child with special needs? | Father Mother |
| How old are you? | |
| What is your educational level? | |
| How much is your monthly household income? | |
| How many children do you have? | |
| How many disabled children do you have? | |
| Is the disabled child your son or your daughter? | |
| How old is your disabled child? | |
| What type of disability does your child have? | |
| What is the ordinal position for your disabled child? | |

Appendix (IV): Interviews schedule⁷

The interview should last around one to one and half hours, it can last longer if parents like. The interview topic will be surrounding parents' experience of special education services, which they and their child have received, starting from the first time they were informed that their child had special needs. I will make sure that parents feel comfortable during the interview, and I will let them know that they have the right to refuse to answer a certain question or even withdraw from the interview.

The following is an example of the types of questions that will be used within the interviews with parents. This schedule is intended to be flexible to allow parents to feel engaged in the interview.

The interview will be semi structured, so the following questions are intended as guidelines only. The order and the style of the questions are not fixed, it is possible to omit some questions or add more questions to obtain more information from the interviewees.

- Could you tell me when you first suspected that your child may have a disability?
- *How did the medical care staff tell you about your child problem, and how did they treat you?*
- *Have the paediatricians or physicians informed you about the available services for your child?*
- *Have you given sufficient information about your child case?*
- *Can you remember your thoughts about the diagnosis you received?*
- *Were the doctors and other medical staff willing to listen to you?*
- *Were you satisfied with the work medical care staff did? Why?*
- *What do you think of the cost of medical care services?*
- Have you tried to obtain an educational diagnosis for your child? If so, how was it?

⁷ Questions in italic that were added for the second phase.

- What do you think about the professional who did the educational diagnosis for your child?
- Was there information available regarding the special education services?
- How did you hear about the special education services?
- Have you gone to the public authorities in order to gain support for your child? Could you tell me about your experience with public sector employees?
- What do you think of accessing the special education services in Jordan?
- What do you think of the cost of special education services?
- What kind of support did you and your child receive from the public authorities?
- Have you received other support from any other resource?
- How did you rate the support that you received from different resources?
- Before your child enrolled in this kindergarten, had you received special education services?
- How did you find out about this kindergarten?
- How difficult was it to enrol your child in this kindergarten?
- Do you feel that you had sufficient choices available to you?
- What do you think of the place where your child received the services?
- Have the education services improved your parental skills, how?
- Do you think your child's development has been improved by the services, if so how?
- To what extent have these services met your child needs?
- Do you think the time which your child is spending in the kindergarten is enough?
- What about the contact with the kindergarten?
- What do you think of the people who are working in the kindergarten? Their competencies, dealing with children, and understanding your needs?
- Do you feel that the kindergarten fees are reasonable?
- What are the strengths and weaknesses in the programme which is presented to your child?

- To what extent are you satisfied with the programme that your child is receiving?
- Have you taken part in making any decisions about your child's progress?
- Have you accompanied your child to the kindergarten? Why?
- Have you shared the kindergarten's staff in your child's education process?
- Have you attended any kindergarten meetings?
- Do you think your involvement in educating your child could improve your child's skills?
- What do you expect from the special education programmes to do for you and your child?
- *What are the problems that you encounter as a parent of child with special needs?*
- What do you suggest to enhance the special education services for children with disabilities?

Appendix (V): Sample of the interview

Mizyed: Could you tell me in details when first time you suspected that your child had a disability?

The father: The first thing, my son was delayed in walking and articulation. I knew that because my first daughter started walking and speaking when she was one year old. He was infected with severe pneumonia for a period of time and he stayed in the hospital for 17 days. During this period, his temperature was 39.5 to 40 degrees. This gave me an indication that my child might have problems in his development. His body was weak. So, he was susceptible to any disease. You know, I recognised all types of antibiotics which exist in the world, I mean if you give me now a name of any antibiotic I can easily tell you what this antibiotic is used for. So, sometimes when he was being ill, I was telling his mum no need to go to the doctors. He was admitted the hospital continuously. When he reached the age of three years old, he started walking. I thought this delay was as a result of a disease or might be the high temperature that had affected him. So I had an indicator that he would have a problem, but he did begin to speak later. Socially he was normal or acceptable, I mean not introvert. The real problem which made me start saying there was something wrong, was that when he became four years old, I took him to a normal kindergarten, but the teachers were not happy with him as he was hyperactive. His mum was a teacher in the same kindergarten; that's why they didn't reject him. His mum kept telling me that "Khaled isn't working well in the kindergarten and his achievement is poor". So, we started looking for the reason. I told myself, "Probably, hyperactivity is the reason. What is the solution for hyperactivity?" This was in 2008 approximately. So, we have been told we should have done medical tests for him.

My medical journey started from the first visit to a neurologist and the brain tests. I organised a CT scan for his head, and enzyme tests. Everything was normal. I mean no one had told me he had a problem. The nerves were ok and all tests were ok. So, I started thinking what his problem was. There was a friend of my wife's sister; she was studying learning difficulties. She advised us to do an educational test for him. I had done an I.Q test for him before in X centre, but the test was out of date, so I was

dissatisfied with it as I had taken some modules in psychology when I was a student in the University and I had an idea about I.Q tests. So I asked her to do the I.Q test in her college because they had well educated people using a Jordanian version of the I.Q test. The person who had done the I.Q test told me “Your son has learning difficulty”. At least we knew his classification. But this was not a disability, this meant a problem in learning; he needed educational specialists. So we started bringing teachers to our home in order to educate him. The teachers didn’t continue their work with him; they came for a short time and then they ceased working with him. My son didn’t improve much; he recognised some letters and numbers.

Later, I started thinking about schooling. We got a new neighbour; she was a doctor in special education and she owns a centre for children with special needs. This lady became a friend of my family. I showed her my son’s reports. I still remember that when we were sitting by the sea and we were happy, she came and told me, “Rest yourself your son has intellectual disability. This isn’t a learning difficulty nor slow learning, this is intellectual disability”. Candidly, I was shocked as I knew her intelligence and her knowledge. She had graduated from a Western country. I stayed for one month without having any word with her. I considered her as an enemy.

During that month I was living in a state of shock and rejection, then a challenging level and finally we reached the acceptance and surrender to our actual situation. She was completely aware and understanding of my reactions, so she dealt with me as a one of her case studies. So I started thinking about what solutions I had. Then, I began to communicate with the lady. I had a chat with her. She told me, “Your son should be enrolled in my centre”. I told myself, “Let’s go and have a look at her centre”. In her centre there were no classrooms, there were different materials like mud and ceramic and children were playing and constructing shapes. I asked the lady, “Do you have classrooms?” she told me, “Sorry we don’t have”. I felt that it was time consuming rather than educational situation, so I refused to enrol my son in her centre. To be honest, her centre had many types of disabilities: intellectual, hearing, visual, cerebral palsy, and emotional. I thought the children in her centre were more severe than my child’s status. So if my child enrolled there, he wouldn’t improve at all, he might relapse. So I chose a private kindergarten attached to centre

for special needs children near our home, I knew about this special kindergarten via the internet. The main problem at that time was how our family would accept that, “My son was in a normal kindergarten and now he is in a kindergarten for disabled children”. I mean, when the kindergarten’s bus came to our home to pick up my child, my mother in law saw the bus, and she noticed what was written on the bus: “Centre for special education”. She stayed two weeks crying. And my mother was disappointed and depressed.

Mizyed: Could you tell me more about your experience with the medical staff in your child’s case?

The father: I want to tell you that, all doctors who I dealt with were governmental doctors, so they never had personal financial benefits; I mean I have never been exploited by any doctor. But, I had a feeling that they didn’t understand me, for example I was trying to explain my child’s case to the paediatrician. Because I had searched many times on the internet about my child’s problem, I knew better than them. There were studies in the western countries about my child’s case and they had no knowledge.

One of my bad experiences was one day I heard about a specialist who had a child with disability, and he had professionals in his centre. I went to see that person in order to find out what my child exactly had. He told me about himself. He had a disabled child and he went to Sweden to have an experience about dealing with children with special needs, and then he recruited a Swedish professional in his centre. I sat with the Swedish expert and discussed my child’s case with her. Unfortunately I was asked to pay a great amount of money also I had to drop him off and pick him up every day. It was impossible for me to do so due to my work condition, also my salary with my wife’s salary couldn’t meet the fees. I had been promised by him to get a discount and he did. The amount after the discount was 4200 JD but it was still too much. Later, I took my child there to get a diagnosis. The experts had taken my child to the next room for 30 minutes then they came back telling me that, “Your child has a learning difficulty”, and they gave me a sheet on which was written: “He can’t tie his shoes, he can’t...., he can’t...” I told them,

“Thank you I’ll think about your offer and get back to you”. They told me, “Wait, you have to pay the consultation fee”. I paid 100Jd. I was so angry because those people were making money out of people’s disasters. So this was one of my bad experiences which I still remember.

Mizyed: So you were dissatisfied with the doctors’ approach when they were dealing with your child’s case?

The father: They never understood what I was saying to them. I was aware about what I was saying because I had done some reading on the internet, but they didn’t know. When I told the neurologist that, “My son’s comprehension is at a low level”, he told me, “The CT scan indicates nothing wrong”. The enzyme specialist was the same. I had a feeling that there was no connection between the specialists. Each one was independent. He might be a creator in his own topic, but he didn’t know other important things related to his topic. The paediatricians recognised that my son had a problem, but they couldn’t recognise what the problem was. They kept referring me to other departments. You know I’m still going there for medical checks and so far they don’t have an idea about the institutions that could serve children with disabilities in Jordan.

Mizyed: You told me you have done several diagnoses for your child? Could you tell me why?

The father: The main point is that I wasn’t convinced that my child had a disability, especially when the doctors were talking about genetics. Neither any member of my wife’s family nor my family had a disability, so I was telling myself: “It might be something ambiguous and doctors couldn’t understand it. This might resolve my child’s problem”. So I was unconvinced and in a denial although I just told you I surrendered, but I was having a hope there was something wrong in the diagnosis and I still have this hope. For example, my child has sinuses in his nose, I have been told these sinuses have no effect on him but I think if we remove these sinuses, his growth will improve and his disability may disappear. You know, the hope is never

stubbed out unless the human dies. The hope never fades. I still have a hope that my child's disability will disappear, even by a miracle.

Mizyed: From your experience, did you find it easy to get information regarding the available services for children with special needs?

The father: It is absolutely difficult. You can't find announcements about the services, neither from public sector nor private sector. I'm always wondering why the government didn't, so far, run a site explaining the availability of services for children with disabilities, and the procedure to get it. The HCAPD has his own site, but they didn't publish a clear procedure of getting the services. Why don't they put ads on the TV or produce programmes about the suspicious of the disability. You know, I think all parents have struggled with diagnosis their disabled children. The diagnosis here is still beginning; it should depend on the environment, I mean here you feel it's like commerce. For example, when I read some reports of my child, I swear its copy and paste. The last diagnosis I got was from the centre for early detection which is managed by the ministry of health. It was the best, but it had been done rapidly which made me suspect that the diagnosis was inaccurate.

Mizyed: Have you received a comprehensive report about your child's abilities?

The father: Frankly, the reports weren't convincing. All of them, particularly private centres gave me reports which included his abilities in different skills but it was less than his real abilities. You know why they did it like this? To make me feel my son was in need of their services such as speech therapy, occupational therapy, and physiotherapy. This would let them ask for extra fees.

Mizyed: You as a parent of a child with disability, have you received any services?

The father: The centre where my son enrolled is conducting a monthly meeting, on the last Saturday in every month. Each meeting deals with different topic; for example the last meeting was named "Autism". You know, we meet different parents during these meetings but unfortunately there is no rapport between the parents at all. When we meet no one tries to get another's contact number. We only have a little

discussion, but there is no connection between us. So far there is no association or place or anything for the parents of children with disability to get together.

Mizyed: Why do you think there is no connection between the parents of children with disabilities here?

The father: Because there is no place to gather them; I mean if there is a place like a society for the parents of children with special needs, probably we feel that we have rules in this society. We may conduct regular meetings, discuss our matters, and host specialists in different subjects. But unfortunately we don't have such a thing. So if there is an association for the parents, it will encourage the parents to get together and build a good rapport between them. They can share their experiences in this association. They will have a stronger voice to defend their children's rights. Also this association may clarify the rights for children with special needs and their parents. Especially, there is a significant number of uneducated parents who don't know their child's rights. You know I can say that most parents of disabled children don't know about the HCAPD. So we need to be connected together in order to help people to identify their children's needs and then find out appropriate places for them. We can get benefits by exchanging our experiences. Probably, the HCAPD will help in establishing an association for the parents. Honestly, I'm convinced that the HCAPD will be more improved since Prince Raad is working in it. He is working there like any full time employee. I wish the HCAPD would be able to deal with all the negative points regarding the disability issue.

Mizyed: Do you think there are services available for parents of children with disabilities in Jordan?

The father: Absolutely not, neither from the public sector nor private sector; I mean the parents should make huge efforts and depends on themselves to get the services. For example, if you want information about your child's case, you won't easily find it. You have to ask here and there. You have to search through the internet. You never find a public body which serves and advises you to deal with your child.

Mizyed: What are the challenges you have faced as a parent of a child with special needs?

The father: First of all, special education services are very expensive; I mean my son costs me a high amount of money. So the person who has a child with a disability, may Allah be with him. I don't know if this is the real cost of the services or the centres exaggerate their claim. I think they are commercial. What I want to say is that if you want to get a high standard of service for your child, you have to pay. To do so, you should receive a high income to be able to get this kind of service. Actually, the services aren't cheap at all. Most likely, now, the HCAPD will share the cost with me, but they don't pay more than 72JD and I pay the rest. Some of special education centres require a high fee, like 450JD a month while the teacher or the normal employee receives 300 JD a month as a salary. Can you imagine how it's difficult if the normal employee has got a child with a disability? How he can pay the fee for his child?

You know, sometimes I can read in the people's eyes the question: "What did you do in your past life?" I mean they assume that Allah has punished me. Others, like my relatives, feel pity for me, which is a bad feeling. I hate the pity feeling. I don't need it; it's breaking something inside me. It generates a feeling of bereavement and weakness. Actually, some of our community's behaviour may make parents withdrawn and introspective. Some parents tend to refuse to deal with their communities fearing from their views. My oldest daughter is studying special education in order to help her brother. She told me, "I will never get married as my brother is disabled. One day when a man comes asking to get married to me, he will reject me when he knows that I have a disabled brother". This is how our community looks at the disability. In addition, we always have an emergency law in our home. We have to be always alert; because you can't anticipate his response. Consequently, I have to stay for a long time in my office to be able to concentrate and write a certain thing. Also, if I want to take part in any social activity, I can't find anyone to stay with my kids. One more problem is that, sometimes there are arguments between me and my wife about meeting his requirements. These are the main problems that I encounter.

Mizyed: Have you received support from your family?

The father: My mother and father in law were volunteering when we had a necessary social activity; they were looking after our kids when we went out. It was impossible to take our kids with us because we didn't want to explain my child case to the other people. Sometimes my son says something wrong. He doesn't understand what he is saying, and he might cause offense. This kind of support I received from my relatives. You know, when we came back from outside, our relatives kept complaining about my child's behaviours.

Mizyed: What do you think of the staff who are working in your child's kindergarten, their competencies, dealing with you and your child?

The father: The staff are qualified; they understand and accept the children. I don't have any problem with them. I feel that they deal with the children perfectly. At least this is what I see. I don't know if they work differently behind back. My daughter is studying special education and she was a trainee in a special education centre. She told me that, "They deal with the children in a different way when the parents aren't there. They sometimes deal with children cruelly". But I think my son's teachers understand my child's needs. I always feel they are qualified.

But there is a big problem I would like to talk about which is a rapid turn-over the teachers. Every visit I went to the centre, I found a new teacher in the classroom, and some had left. You know this policy would affect the learning process. In Jordan we had qualified specialists for children with disabilities, but most of them went to the Gulf countries. I think it's their right to find a better offer and better salary. But the new teachers don't have enough experience and training to work with our kids. In the past, teachers were sending me my child's program and his objectives, what he's achieved and what's left, but now they have stopped doing that. I don't see any report.

Mizyed: What do you think of the place where your child is being educated?

The father: This centre was going to be closed this year. I'll tell you the reason. The MoSD requires specific conditions to run a special education centre. One of these conditions is that the building of the centre should be separated, have its own paths, and the net capacity should be appropriate. Now the number of children who are enrolled in this centre is twice as high as its capacity, and in this building there is a residential apartment, so the MoSD gave them a chance to correct their situation. To be honest, I can't say whether the building is good or not. It's relatively new but it doesn't have any yard or play ground. There are some toys that were put in the front, but I have never seen any child using them. They are put in a small space probably less than this office; they might be there put in order to show the parents that, "There are toys in our centre". The classrooms are quite small; some of this classrooms are less than 2m x 2.5m. Frankly, most special education centres are commercial centres. My child's centre is one of the best of them. It was established by parents (father and mother) of two daughters with disability, and they started working by offering services for children who were similar to their daughters' case. But now their intention has changed; they have become more concerned with the money rather than the services. They increased the fee several times and they had problems in the net capacity with the MoSD. So I have the feeling that those parents aren't interested in human issues, they are interested in making money.

Mizyed: What do you think of the geographical site of your child's centre?

The father: The site is acceptable; it's near to our house. Even if it's far away, this kind of centres offers transportation from your door to the centre as it's in the private sector. The site is near to the main road but it's far from the noise; it's a quiet area.

Mizyed: Have you been involved in constructing your child's objectives or planning his curriculum?

The father: This practice doesn't exist in Jordan. I never heard that in Jordan there is a school or kindergarten which involves the parents in such a thing. My daughter told me that, "In America parents of children with special needs are an important part of developing the curriculum for their disabled children". But, here sometimes they

don't let us know details about the curriculum. They only let you see the part that they are going to achieve. I saw some of these objectives written on my son's notebook. For example, "The object this week is recognising two colours, counting number 1 and 2", but they never told me that this our curriculum or anything so we could follow them. They never asked me, "What do you want your son to learn?"

Mizyed: Have you asked the teacher to teach your son a certain skill?

The father: No, never. But they told us: "Try to know what your child enjoys doing". They wanted to know what our child likes to do in order to encourage this thing. For example, we told them that our son enjoys helping his mother in preparing the food and cooking. Then they told us, "We will develop this skill". But they didn't. Actually, they don't have training on vocational rehabilitation. I mean the centres of special education in Jordan are still suffering from a shortage of different things. The problem is that there is no coordination between the MoE, HCAPD, and MoSD in supervising the centres.

Mizyed: How often do you visit your child in his kindergarten (centre)?

The father: I was tracking his progress continuously. I was visiting them once a month, but I have never been to his classroom. I was watching him in the classroom without letting the teacher see me. But I never attended his classroom. Teachers were sometimes teaching him things which put me in trouble, in my home. For example, the concept of secret. So I couldn't speak to my son. When I asked him a question he kept telling me, "No, I can't tell you, this is a secret". Everything in his life became a secret. I phoned his teacher telling her that she shouldn't have taught them that everything in his life is a secret.

Mizyed: Do you think your son's development has been improved by the services that he is receiving? How?

The father: At the beginning yes, but later no. I mean the first time he enrolled in this kindergarten, he improved in some skills like primary academic skills; they started with him from zero, then he learnt some numbers and letters. After that he stopped

improving. It's like they reached a limit and they couldn't exceed it. I feel that he learnt counting till number 5 and nothing came after. Also, he tended to copy his colleagues in the classroom. I mean if there is a child in his classroom who has stereotyped behaviour, he brings this behaviour to our home.

Mizyed: Did you talk to his teacher about this behaviour?

The father: Of course I did. I told them everything and they understood; they tried to change these behaviours. But the problem is every day he comes with new annoying behaviour.

Mizyed: What do you suggest to enhance the special education services for children with disabilities?

The father: The first issue is unifying the efforts between the bodies who are supervising the special education services. Through their unity, they can clearly recognise what is being delivered to the community. But now there is dispersal of their efforts; there is no one main body to manage the matter. The second issue is that there should be an active role by the parents themselves in making decisions. They should be enrolled in an association or society or group or whatever, so they can get together, discuss, exchange their experiences, and at the same time they could be a strong power in order to achieve the appropriate services. This is the most important thing I'm thinking about and asking for.

The other issue is that, the support; it should be the responsibility of a public authority to support children with disabilities financially; I mean the government's centres are the worst centres in Jordan compared with the private sector; they provide a low level of services. It doesn't have well-qualified staff, it doesn't have suitable equipment and tools, and it serves only a limited number of children with disabilities. The government should establish centres and make these centres better than the private sector, or at least develop the current centres. The HCAPD should establish improved public schools rather than paying part of children fees. That will be saving money in the future. If the HCAPD is doing so, it will help the parents to lift their burden and avoid them from being exploited by the private sector. Sometimes I feel

these centres are for making money rather than providing human services. Why don't the HCAPD adopt this issue? Why don't they establish high standard centres and recruit qualified people and then serve all disabled children regardless of their financial position?

For the diagnosis issue, there should be a one centre for diagnosis in Jordan and this centre should be controlled by the HCAPD. Now each centre has its procedure in diagnosis or bringing a test from outside and applies it to our children. If they test our child by using materials from other countries, the results surely will be wrong. We need tests that understand our culture and the nature of Jordanian society.

Mizyed: To what extent you are satisfied with the special education services?

The father: I'm satisfied when I compare the services with other Arabian countries. But when I see the services in western countries, I'm completely dissatisfied. Anyway, we thank and praise Allah as we have got services. It's better than nothing.

Mizyed: Thank you very much for giving me this opportunity to talk to you.

Appendix (VI): Sample of coded text

| Initial code | Text |
|--|---|
| <ul style="list-style-type: none"> • Communication with healthcare professionals • Reassurance • Shock | While I was pregnant, I asked my doctor to do some tests to make sure that everything was going ok. I told him, "I am too old", but he replied that I had a healthy child and everything was fine, so no need to be worried. We do not have any Mongolism cases in both families, so I was shocked when they told me that my child had Down's syndrome. |
| <ul style="list-style-type: none"> • Informing parent about the diagnosis | I still remember, the doctor was unkind. (My husband was not there). The doctor came and told me directly, "Your daughter has Down's syndrome". The doctor was talking unkindly. |
| <ul style="list-style-type: none"> • Shock • Withdrawal | I was completely shocked. I didn't want anyone to talk with me, I also didn't want to see anyone. This is because my son was 6 years old and I was very happy as I was waiting for a new baby girl. |
| <ul style="list-style-type: none"> • Movement between doctors • Denial • Lack of information about the available services | The same day, we took her to another doctor. We did the examination of chromosomes for her and the disability was confirmed. Then we looked for anything to guide us where to go or what to do but we found nothing. After this we looked for specialist centres, but none was found. |
| <ul style="list-style-type: none"> • Teachers not qualified enough • Need for information | Let's talk frankly: the centres' teachers here helped us a little; they gave us some training with our daughter, but they don't have enough experience and they are not specialists in Down's syndrome. We, as parents, need information about how to treat our daughter. There is no one to give such a thing. |

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| <ul style="list-style-type: none"> • Dissatisfaction with professional of diagnosis • Dissatisfaction with the instrument • Cost of diagnosis | <p>Yes we did an IQ test, but we don't trust it at all, because the one who did it is not qualified enough. I'm not convinced with the test and the tools that he used. I think he couldn't build a good rapport with our daughter so she didn't respond to him correctly. So far, I can't understand why he asked me to pay 120 JD.</p> <p>What did he do?</p> |
| <ul style="list-style-type: none"> • Classroom teachers, their skills and qualifications • Centre outcome | <p>The teachers here are doing their best. They improved her skills but they are not qualified enough. They have a general idea about Down's syndrome, but not the details. They can't meet all the needs of Down's syndrome children. There are a lot of things they still didn't know, and they have to train the parents before the child.</p> |
| <ul style="list-style-type: none"> • High fees-private sector • Lack of public services • Building of the centre • Centre outcome • Fears for the future | <p>There are a lot of private schools in Amman but they ask you to pay much higher fees; it becomes like a business..The building of the kindergarten is so bad; honestly. There is no enough space or equipment; there is nothing suitable there. However, we pay a lot of money to these centres for nothing; the children are just spending the whole day in the centre. We can pay now for our daughter but what if we cannot help her and take care of her and what will happen to her when we die? Who will help her?</p> |
| <ul style="list-style-type: none"> • Lack of support • Lack of information • Certainty • Need for information | <p>We heard about support, but practically there was no support. The first time I visited the MoSD, I asked for help or at least information about Down's syndrome. I needed to know what is expected from her.</p> <p>They told me to live with her day by day and I would see what would happen. They don't have any details about Down's syndrome.</p> |

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| <ul style="list-style-type: none"> • Dissatisfaction with the services | <p>We are not satisfied at all with the provision for young children with intellectual disability. If you ask me to rate the services out of five, I will give it minus five. They don't even have the information.</p> |
| <p>Parents suggestions</p> <ul style="list-style-type: none"> • Providing information • Providing financial support for parents and their children • Providing psychological support for parents • Providing pertinent courses for parents | <p>I suggest that the government or the MoH should publish brochures about Down's syndrome like the ones they made for birth control. Such as simple leaflets which include what is expected from intellectually disabled children of different ages. We look for support and search for the information, so the most important thing is the courses for the parents of disabled children. We need books about Down's syndrome to read, leaflets or at least website. We also need institutions to support us psychologically from the moment we know that our child has a problem. There should be government department which give for financial support, because not all people can pay for their disabled children. You know how high the special education services costs are.</p> |

“Thank you I’ll think about your offer and get back to you”. They told me, “Wait, you have to pay the consultation fee”. I paid 100Jd. I was so angry because those people were making money out of people’s disasters. So this was one of my bad experiences which I still remember.

Mizyed: So you were dissatisfied with the doctors’ approach when they were dealing with your child’s case?

The father: They never understood what I was saying to them. I was aware about what I was saying because I had done some reading on the internet, but they didn’t know. When I told the neurologist that, “My son’s comprehension is at a low level”, he told me, “The CT scan indicates nothing wrong”. The enzyme specialist was the same. I had a feeling that there was no connection between the specialists. Each one was independent. He might be a creator in his own topic, but he didn’t know other important things related to his topic. The paediatricians recognised that my son had a problem, but they couldn’t recognise what the problem was. They kept referring me to other departments. You know I’m still going there for medical checks and so far they don’t have an idea about the institutions that could serve children with disabilities in Jordan.

Mizyed: You told me you have done several diagnoses for your child? Could you tell me why?

The father: The main point is that I wasn’t convinced that my child had a disability, especially when the doctors were talking about genetics. Neither any member of my wife’s family nor my family had a disability, so I was telling myself: “It might be something ambiguous and doctors couldn’t understand it. This might resolve my child’s problem”. So I was unconvinced and in a denial although I just told you I surrendered, but I was having a hope there was something wrong in the diagnosis and I still have this hope. For example, my child has sinuses in his nose, I have been told these sinuses have no effect on him but I think if we remove these sinuses, his growth will improve and his disability may disappear. You know, the hope is never

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stubbed out unless the human dies. The hope never fades. I still have a hope that my child's disability will disappear, even by a miracle.

Mizyed: From your experience, did you find it easy to get information regarding the available services for children with special needs?

The father: It is absolutely difficult. You can't find announcements about the services, neither from public sector nor private sector. I'm always wondering why the government didn't, so far, run a site explaining the availability of services for children with disabilities, and the procedure to get it. The HCAPD has his own site, but they didn't publish a clear procedure of getting the services. Why don't they put ads on the TV or produce programmes about the suspicious of the disability. You know, I think all parents have struggled with diagnosis their disabled children. The diagnosis here is still beginning; it should depend on the environment, I mean here you feel it's like commerce. For example, when I read some reports of my child, I swear its copy and paste. The last diagnosis I got was from the centre for early detection which is managed by the ministry of health. It was the best, but it had been done rapidly which made me suspect that the diagnosis was inaccurate.

Mizyed: Have you received a comprehensive report about your child's abilities?

The father: Frankly, the reports weren't convincing. All of them, particularly private centres gave me reports which included his abilities in different skills but it was less than his real abilities. You know why they did it like this? To make me feel my son was in need of their services such as speech therapy, occupational therapy, and physiotherapy. This would let them ask for extra fees.

Mizyed: You as a parent of a child with disability, have you received any services?

The father: The centre where my son enrolled is conducting a monthly meeting, on the last Saturday in every month. Each meeting deals with different topic; for example the last meeting was named "Autism". You know, we meet different parents during these meetings but unfortunately there is no rapport between the parents at all. When we meet no one tries to get another's contact number. We only have a little

discussion, but there is no connection between us. So far there is no association or place or anything for the parents of children with disability to get together.

Mizyed: Why do you think there is no connection between the parents of children with disabilities here?

The father: Because there is no place to gather them; I mean if there is a place like a society for the parents of children with special needs, probably we feel that we have rules in this society. We may conduct regular meetings, discuss our matters, and host specialists in different subjects. But unfortunately we don't have such a thing. So if there is an association for the parents, it will encourage the parents to get together and build a good rapport between them. They can share their experiences in this association. They will have a stronger voice to defend their children's rights. Also this association may clarify the rights for children with special needs and their parents. Especially, there is a significant number of uneducated parents who don't know their child's rights. You know I can say that most parents of disabled children don't know about the HCAPD. So we need to be connected together in order to help people to identify their children's needs and then find out appropriate places for them. We can get benefits by exchanging our experiences. Probably, the HCAPD will help in establishing an association for the parents. Honestly, I'm convinced that the HCAPD will be more improved since Prince Raad is working in it. He is working there like any full time employee. I wish the HCAPD would be able to deal with all the negative points regarding the disability issue.

Mizyed: Do you think there are services available for parents of children with disabilities in Jordan?

The father: Absolutely not, neither from the public sector nor private sector; I mean the parents should make huge efforts and depends on themselves to get the services. For example, if you want information about your child's case, you won't easily find it. You have to ask here and there. You have to search through the internet. You never find a public body which serves and advises you to deal with your child.

Mizyed: What are the challenges you have faced as a parent of a child with special needs?

The father: First of all, special education services are very expensive; I mean my son costs me a high amount of money. So the person who has a child with a disability, may Allah be with him. I don't know if this is the real cost of the services or the centres exaggerate their claim. I think they are commercial. What I want to say is that if you want to get a high standard of service for your child, you have to pay. To do so, you should receive a high income to be able to get this kind of service. Actually, the services aren't cheap at all. Most likely, now, the HCAPD will share the cost with me, but they don't pay more than 72JD and I pay the rest. Some of special education centres require a high fee, like 450JD a month while the teacher or the normal employee receives 300 JD a month as a salary. Can you imagine how it's difficult if the normal employee has got a child with a disability? How he can pay the fee for his child?

You know, sometimes I can read in the people's eyes the question: "What did you do in your past life?" I mean they assume that Allah has punished me. Others, like my relatives, feel pity for me, which is a bad feeling. I hate the pity feeling. I don't need it; it's breaking something inside me. It generates a feeling of bereavement and weakness. Actually, some of our community's behaviour may make parents withdrawn and introspective. Some parents tend to refuse to deal with their communities fearing from their views. My oldest daughter is studying special education in order to help her brother. She told me, "I will never get married as my brother is disabled. One day when a man comes asking to get married to me, he will reject me when he knows that I have a disabled brother". This is how our community looks at the disability. In addition, we always have an emergency law in our home. We have to be always alert; because you can't anticipate his response. Consequently, I have to stay for a long time in my office to be able to concentrate and write a certain thing. Also, if I want to take part in any social activity, I can't find anyone to stay with my kids. One more problem is that, sometimes there are arguments between me and my wife about meeting his requirements. These are the main problems that I encounter.

Mizyed: Have you received support from your family?

The father: My mother and father in law were volunteering when we had a necessary social activity; they were looking after our kids when we went out. It was impossible to take our kids with us because we didn't want to explain my child case to the other people. Sometimes my son says something wrong. He doesn't understand what he is saying, and he might cause offense. This kind of support I received from my relatives. You know, when we came back from outside, our relatives kept complaining about my child's behaviours.

Mizyed: What do you think of the staff who are working in your child's kindergarten, their competencies, dealing with you and your child?

The father: The staff are qualified; they understand and accept the children. I don't have any problem with them. I feel that they deal with the children perfectly. At least this is what I see. I don't know if they work differently behind back. My daughter is studying special education and she was a trainee in a special education centre. She told me that, "They deal with the children in a different way when the parents aren't there. They sometimes deal with children cruelly". But I think my son's teachers understand my child's needs. I always feel they are qualified.

But there is a big problem I would like to talk about which is a rapid turn-over the teachers. Every visit I went to the centre, I found a new teacher in the classroom, and some had left. You know this policy would affect the learning process. In Jordan we had qualified specialists for children with disabilities, but most of them went to the Gulf countries. I think it's their right to find a better offer and better salary. But the new teachers don't have enough experience and training to work with our kids. In the past, teachers were sending me my child's program and his objectives, what he's achieved and what's left, but now they have stopped doing that. I don't see any report.

Mizyed: What do you think of the place where your child is being educated?

The father: This centre was going to be closed this year. I'll tell you the reason. The MoSD requires specific conditions to run a special education centre. One of these conditions is that the building of the centre should be separated, have its own paths, and the net capacity should be appropriate. Now the number of children who are enrolled in this centre is twice as high as its capacity, and in this building there is a residential apartment, so the MoSD gave them a chance to correct their situation. To be honest, I can't say whether the building is good or not. It's relatively new but it doesn't have any yard or play ground. There are some toys that were put in the front, but I have never seen any child using them. They are put in a small space probably less than this office; they might be there put in order to show the parents that, "There are toys in our centre". The classrooms are quite small; some of this classrooms are less than 2m x 2.5m. Frankly, most special education centres are commercial centres. My child's centre is one of the best of them. It was established by parents (father and mother) of two daughters with disability, and they started working by offering services for children who were similar to their daughters' case. But now their intention has changed; they have become more concerned with the money rather than the services. They increased the fee several times and they had problems in the net capacity with the MoSD. So I have the feeling that those parents aren't interested in human issues, they are interested in making money.

Mizyed: What do you think of the geographical site of your child's centre?

The father: The site is acceptable; it's near to our house. Even if it's far away, this kind of centres offers transportation from your door to the centre as it's in the private sector. The site is near to the main road but it's far from the noise; it's a quiet area.

Mizyed: Have you been involved in constructing your child's objectives or planning his curriculum?

The father: This practice doesn't exist in Jordan. I never heard that in Jordan there is a school or kindergarten which involves the parents in such a thing. My daughter told me that, "In America parents of children with special needs are an important part of developing the curriculum for their disabled children". But, here sometimes they

don't let us know details about the curriculum. They only let you see the part that they are going to achieve. I saw some of these objectives written on my son's notebook. For example, "The object this week is recognising two colours, counting number 1 and 2", but they never told me that this our curriculum or anything so we could follow them. They never asked me, "What do you want your son to learn?"

Mizyed: Have you asked the teacher to teach your son a certain skill?

The father: No, never. But they told us: "Try to know what your child enjoys doing". They wanted to know what our child likes to do in order to encourage this thing. For example, we told them that our son enjoys helping his mother in preparing the food and cooking. Then they told us, "We will develop this skill". But they didn't. Actually, they don't have training on vocational rehabilitation. I mean the centres of special education in Jordan are still suffering from a shortage of different things. The problem is that there is no coordination between the MoE, HCAPD, and MoSD in supervising the centres.

Mizyed: How often do you visit your child in his kindergarten (centre)?

The father: I was tracking his progress continuously. I was visiting them once a month, but I have never been to his classroom. I was watching him in the classroom without letting the teacher see me. But I never attended his classroom. Teachers were sometimes teaching him things which put me in trouble, in my home. For example, the concept of secret. So I couldn't speak to my son. When I asked him a question he kept telling me, "No, I can't tell you, this is a secret". Everything in his life became a secret. I phoned his teacher telling her that she shouldn't have taught them that everything in his life is a secret.

Mizyed: Do you think your son's development has been improved by the services that he is receiving? How?

The father: At the beginning yes, but later no. I mean the first time he enrolled in this kindergarten, he improved in some skills like primary academic skills; they started with him from zero, then he learnt some numbers and letters. After that he stopped

improving. It's like they reached a limit and they couldn't exceed it. I feel that he learnt counting till number 5 and nothing came after. Also, he tended to copy his colleagues in the classroom. I mean if there is a child in his classroom who has stereotyped behaviour, he brings this behaviour to our home.

Mizyed: Did you talk to his teacher about this behaviour?

The father: Of course I did. I told them everything and they understood; they tried to change these behaviours. But the problem is every day he comes with new annoying behaviour.

Mizyed: What do you suggest to enhance the special education services for children with disabilities?

The father: The first issue is unifying the efforts between the bodies who are supervising the special education services. Through their unity, they can clearly recognise what is being delivered to the community. But now there is dispersal of their efforts; there is no one main body to manage the matter. The second issue is that there should be an active role by the parents themselves in making decisions. They should be enrolled in an association or society or group or whatever, so they can get together, discuss, exchange their experiences, and at the same time they could be a strong power in order to achieve the appropriate services. This is the most important thing I'm thinking about and asking for.

The other issue is that, the support; it should be the responsibility of a public authority to support children with disabilities financially; I mean the government's centres are the worst centres in Jordan compared with the private sector; they provide a low level of services. It doesn't have well-qualified staff, it doesn't have suitable equipment and tools, and it serves only a limited number of children with disabilities. The government should establish centres and make these centres better than the private sector, or at least develop the current centres. The HCAPD should establish improved public schools rather than paying part of children fees. That will be saving money in the future. If the HCAPD is doing so, it will help the parents to lift their burden and avoid them from being exploited by the private sector. Sometimes I feel

these centres are for making money rather than providing human services. Why don't the HCAPD adopt this issue? Why don't they establish high standard centres and recruit qualified people and then serve all disabled children regardless of their financial position?

For the diagnosis issue, there should be a one centre for diagnosis in Jordan and this centre should be controlled by the HCAPD. Now each centre has its procedure in diagnosis or bringing a test from outside and applies it to our children. If they test our child by using materials from other countries, the results surely will be wrong. We need tests that understand our culture and the nature of Jordanian society.

Mizyed: To what extent you are satisfied with the special education services?

The father: I'm satisfied when I compare the services with other Arabian countries. But when I see the services in western countries, I'm completely dissatisfied. Anyway, we thank and praise Allah as we have got services. It's better than nothing.

Mizyed: Thank you very much for giving me this opportunity to talk to you.

Appendix (VI): Sample of coded text

| Initial code | Text |
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| <ul style="list-style-type: none"> • Communication with healthcare professionals • Reassurance • Shock | While I was pregnant, I asked my doctor to do some tests to make sure that everything was going ok. I told him, "I am too old", but he replied that I had a healthy child and everything was fine, so no need to be worried. We do not have any Mongolism cases in both families, so I was shocked when they told me that my child had Down's syndrome. |
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| <ul style="list-style-type: none"> • Classroom teachers, their skills and qualifications • Centre outcome | <p>The teachers here are doing their best. They improved her skills but they are not qualified enough. They have a general idea about Down's syndrome, but not the details. They can't meet all the needs of Down's syndrome children. There are a lot of things they still didn't know, and they have to train the parents before the child.</p> |
| <ul style="list-style-type: none"> • High fees-private sector • Lack of public services • Building of the centre • Centre outcome • Fears for the future | <p>There are a lot of private schools in Amman but they ask you to pay much higher fees; it becomes like a business. The building of the kindergarten is so bad; honestly. There is no enough space or equipment; there is nothing suitable there. However, we pay a lot of money to these centres for nothing; the children are just spending the whole day in the centre. We can pay now for our daughter but what if we cannot help her and take care of her and what will happen to her when we die? Who will help her?</p> |
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| <p>Parents suggestions</p> <ul style="list-style-type: none"> • Providing information • Providing financial support for parents and their children • Providing psychological support for parents • Providing pertinent courses for parents | <p>I suggest that the government or the MoH should publish brochures about Down's syndrome like the ones they made for birth control. Such as simple leaflets which include what is expected from intellectually disabled children of different ages. We look for support and search for the information, so the most important thing is the courses for the parents of disabled children. We need books about Down's syndrome to read, leaflets or at least website. We also need institutions to support us psychologically from the moment we know that our child has a problem. There should be government department which give for financial support, because not all people can pay for their disabled children. You know how high the special education services costs are.</p> |